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ABSTRACT

This monograph is based on an international survey of approximately 60 individuals/organizations concerning the nature of disability and disability awareness. The survey was part of a project of the International Exchange of Experts and Information on Rehabilitation which is attempting to make information about disability issues from other countries available to U.S. audiences. The three papers in this monograph give special attention to disability issues in Africa. In "Changing Beliefs about Disability in Developing Countries: Historical Factors and Sociocultural Variables," Bruce L. Mallory identifies salient themes from the survey grouped into six categories: (1) cultural values, (2) attribution theories, (3) attitudinal responses, (4) institutional effects, (5) adaptability and change in belief systems, and (6) nature of the disability. Examples from three developing countries (Zaire, Kenya, and Thailand) illustrate the themes. In the second paper, "An Examination of Some Traditional African Attitudes towards Disability," Robert W. Nicholls compares the beliefs and behaviors of disparate ethnic groups including the Igede, Igbo, and Yoruba of Nigeria, and the Ndembu of Zambia. The third paper is by James I. Charlton and is titled "Development and Disability: Voices from the Periphery - Zimbabwe." Charlton addresses the contradictions that the disability rights movement in Zimbabwe confronts within the economic, cultural, and political milieu of Zimbabwe. A commentary on the papers is provided by Kofi Marfo, followed by a rejoinder written by Robert W. Nicholls. An appendix lists sample answers to survey questions. (DB)

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TRADITIONAL AND [illegible]G VIEWS OF DIS[illegible] IN DEVELOPING SOC[illegible]IES

CAUSES, CONSEQUENCES, CAUTIO[illegible]

Bruce L. Mallory
Robert W. Nichols
James I. Charlton
Kofi Marfo

T[illegible]ional E[illegible]nge of F[illegible]
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Monograph #53

Traditional and Changing Views of Disability in Developing Societies

Causes, Consequences, Cautions

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Preface and Acknowledgments

In 1991 the IEEIR decided to focus on the theme: "The Changing Nature of Disability and Disability Awareness Worldwide." Subsequently, we contacted approximately sixty overseas individuals/organizations in our international network in Asia, the Pacific and Africa and asked them to respond to seven questions in order to reveal existing issues and problems related to this theme. The questions we asked were:

1. In what way are people with disabilities viewed in your society, and how is that changing or not changing?

2. In what ways have the availability of programs and services been improved (or not)?

3. What has been happening there regarding personnel training and professional standards?

4. What role do the family, school, church, and other community organizations play in enabling people with disabilities to participate in society?

5. How has your country responded to needs of family members and used them as resources in the rehabilitation process?

6. How have people with disabilities themselves influenced change?

7. Do you feel that U.S. disability rights advocates should be working with people with disabilities in your country to help them become more aware of their place in society? What suggestions might you have in this regard? (We feel that there is a slowly growing interest on the part of U.S. disability advocacy groups to assist people with disabilities in emerging countries to recognize their own rights and value in society. However, cross-cultural "education" often does not adequately take in to consideration values, mores and attitudes of other countries.) What do you think U.S. disability advocates should know about your country and its disability movement before visiting?

It was our hope that promoting this theme and asking these questions would help to provide a framework for understanding critical information we felt would be important to share in various ways within our U.S. and international network. A variety of responses were received; although only a few responded directly to the questions asked, many shared experiences or materials which they thought could be useful. **We have included the names of the participants and sample responses in the appendix.**

Bruce Mallory, Chair of the Department of Education and special consultant to the IEEIR here at University of New Hampshire, who was working with us on this study, was asked to prepare an article based on the material that was collected through the survey and which was used in the development of the first chapter of this monograph.

In addition to the chapter by Bruce Mallory, which has been an IEEIR work in progress over the past year, the IEEIR has also already published special interest newsletters on the general topic "The Changing Nature of Disability and Disability Awareness Worldwide":

Spring 1991 - "Special Issue on Korea" - Geungkook Kim, Ph.D. and Christina Kimm, Ph.D.

Fall 1991 - "The Changing Nature of Disability Worldwide", a general interest issue of *Interchange*.

November - December 1991 - "The Potential for U.S. - Asia Research Collaboration: Two Examples" - "Using Action-Oriented Disability Studies in Pakistan" by Mike Miles and "Developing Mutual Understanding Between Western and Non-Western Cultures Through Collaborative Research" by Judy Kugelmass, Ph.D. (U.S.) and Kusdwiatri Setiono, Ph.D. (Indonesia)

Spring 1992 - "China's Program of Rehabilitative Medical Services: An 'Outline' for 1991 - 1995" - Chen Zhongqu, M.D. and "Maori Mental Health - Two Perspectives" - Mason Durie, Ph.D.

January 1993 - Culture and Disability in the Pacific - Editors: Maureen Fitzgerald and Jocelyn Armstrong.

Along the way on this cross-national, cross-cultural, cross-disability journey we read Robert Nicholls' very interesting unpublished article on attitudes in Africa and saw a place for it in this monograph. James Charlton, another contributor to this monograph, had been awarded an IEEIR fellowship to look at empowerment and the experience and development of advocacy ideas and advocacy groups in Zimbabwe. Although reports of IEEIR fellowships are usually distributed as unpublished reports, this one, with its personal interview format and its emphasis on the economic aspects of disability was unique and "fit" the "Changing Nature of Disability Awareness" theme so well that we felt compelled to include it.

Once we had decided to put together the Mallory, Nicholls and Charlton pieces under one cover, we then decided to get commentary from an African national. With his particular background, Kofi Marfo was a logical person to do this, and his contribution helps significantly to tie together the other three

pieces while at the same time offering constructive criticism to the authors and suggestions for further research. As Professor Marfo indicates:

> "The three papers in this monograph address some of the fundamental contextual variables about which international disability experts must become knowledgeable if they are to make meaningful contributions to the quest for effective strategies and programs to deal with the growing problem of disability in developing countries. Although the papers vary drastically in writing style and draw examples and experiences from different parts of Africa (Mallory's paper even includes a case study of Thailand), they deal with a continuum of interconnected themes. In this regard, the papers complement one another quite well."

We hope that this monograph provides readers with a different context for viewing disability issues, not only in the developing world, but also, on further reflection, in the U.S. The "colonial" paradigm certainly has a great deal of relevance in looking at, reflecting on, and moving ahead vis-a-vis the changing nature of disability awareness around the globe.

We at last have the opportunity to express "publicly" our gratitude to all of those individuals who took the time to write to us to share information and insights relevant to disability and their country.

We share and support Marfo's (and Mike Miles', Bruce Mallory's, *et al*) admonition that the consciousness that imagines only Western habilitation and rehabilitation interventions to really count does an extreme disservice to the developing world where for the foreseeable future care will continue to be given mainly by relatives, friends, traditional practitioners and disabled people themselves. As Marfo notes:

> "Disability specialists and social science researchers with interest in disability issues must respond to the challenge of finding meaningful ways of interfacing indigenous care and habilitation practices with dimensions of Western approaches that make sense in the context of Third World environments."

We hope that what has drawn you to this publication will be satisfied and that the IEEIR goal of providing U.S. disability specialists with linkages to information from and about other parts of the world will be realized.

Diane E. Woods
IEEIR Project Director
February, 1993

CHAPTER ONE
Changing Beliefs About Disability in Developing Countries: Historical Factors and Sociocultural Variables

Bruce L. Mallory
University of New Hampshire

Bruce L. Mallory is associate professor of early childhood and special education, and chair of the Department of Education, at the University of New Hampshire. He received the Ph.D. in Special Education from George Peabody College in 1979, after working for several years as a secondary social studies teacher, VISTA volunteer, and director of Head Start programs in New Hampshire. Since his appointment at UNH, he has established the graduate program in Early Childhood Special Needs; received personnel preparation and research grants related to early childhood disability and social policy; and published numerous works related to families with disabled children, policies affecting young children with disabilities, and, most recently, the need for inclusive developmentally appropriate practices for preschool children with special needs. During a sabbatical leave in the late 1980's, Dr. Mallory lectured and consulted in Australia, New Zealand, and Malaysia on topics related to developmental disability.

The relationship between cultural belief systems and societal attitudes toward individuals with disabilities has been explored extensively, primarily in literature published in the United States and other industrialized countries (e.g. Farber, 1968; Gleidman & Roth, 1980; Lane, 1988). In general, variations in social attitudes are thought to be associated with economic conditions, the state of medical and therapeutic technology, social policies (and their relation to conceptions of human rights), religious and cultural belief systems, and idiosyncratic factors such as the role of political leaders who take a personal interest in the lives of people with disabilities.

Considerably less is known, at least among experts residing in industrialized nations, about beliefs and attitudes in developing countries with respect to disability, including its cause and the appropriate private and public response. This ignorance is accompanied by Eurocentric interpretations. For example, Nicholls (1992, p. 1) notes the "observable tendency to reduce African ideas about disability to a few hackneyed scenarios whereby disability

is seen either as a result of witch-craft . . . or as a form of divine retribution visited on a negligent individual." In light of the significant changes in attitudes that have occurred in industrialized nations over the past 20 years, and the dramatic economic, political, and social changes now occurring in developing countries, it is appropriate to consider a number of historical and sociocultural issues that could affect belief systems and attitudes in non-Western societies. The critical issues that are of interest in this essay are reflected in the following questions:

1. *Are beliefs and attitudes about disability changing in developing countries? If so, how?*
2. *What are the factors causing these changes?*
3. *What are the consequences of these changes?*
4. *What lessons are there for industrialized countries as a result of these changes?*

Because of the complexity of these questions, and the variable phenomena that exist across developing countries, it is not possible to answer them fully in the present paper. Rather, this essay is intended to raise the issues, suggest critical factors that must be considered in addressing them, and offer some initial conclusions that may serve as the basis for more extensive investigation and analysis in the future.

First, a word about this author's lens is necessary. I am a white, American, temporarily able-bodied male with only brief experiences in developing countries. This perspective certainly restricts my ability to make reliable conclusions, or to interpret the available data through indigenous eyes. Compounding this handicap is the fact that most of the extant sources are written by people more like me than like those people being described.

Related to this shortcoming is the lack of theoretical or methodological models available to guide this type of analysis. Devlieger (1989, p. 1), in discussing the situation in Kenya, writes, "The field of culture and disability as applicable to developing countries is new and only a few contributions have been made so far." Groce (1990) claims that this is an emerging field of inquiry requiring careful framing and methodological attention before any conclusions may be drawn. Furthermore, because the present analysis is based on written material rather than direct observations, we must acknowledge the gap between policy rhetoric and the reality of program implementation. As two observers from Kenya note, "Platitudes and grand principles apart, practice is weaned in contradictions at the societal level and at the institutional level" (Nkinyangi & Mbindyo, 1982, p.41).

My colleague Diane Woods and I, through our work with the World Rehabilitation Fund and the International Exchange of Experts and Informa-

tion in Rehabilitation project, located at the University of New Hampshire, have developed a number of contacts in the fields of rehabilitation and special education in developing countries. In the fall and winter of 1990-91, we wrote to 66 disability specialists and advocates to request any data they might have bearing on the questions listed earlier. We received useful responses from health care and rehabilitation specialists, as well as social scientists, residing in India, Indonesia, Kenya, Malaysia, Nepal, Nigeria, Pakistan, Thailand, and Zaire. Some of the descriptions were written by western observers working in voluntary and governmental organizations or on study visits for the purpose of research or technical assistance; other data sources include indigenous practitioners and academics in the countries in question. The types of documents reviewed include both field-based descriptive reports and official policy-related documents issued by local or national government agencies.

After reviewing the responses to identify salient themes as well as divergent data, it became clear that there are a number of contextual factors related to history, sociocultural values, political and economic circumstances, and geographic influences that must be considered in order to understand changing attitudes toward people with disabilities. The present paper begins with a theoretical framework concerning cultural influences on parenting and child development. This framework is then used as a context for understanding historical factors related to colonial occupation and missionary activity. Next, the specific emergent themes that arose from the materials provided by our international respondents are outlined. Finally, examples from three countries (Kenya, Thailand, and Zaire) illustrating the historical factors and emergent themes are offered and tentative conclusions are suggested.

Cultural Influences, Economic Conditions, and Child Rearing

One way to distinguish between developed countries (also referred to as industrialized, modern, or western) and developing countries (also referred to as traditional, third world, or non-western) is by describing the economic relationship between children and their parents. In developed countries, resources flow from parents to children. That is, parents are expected to provide almost total economic support to their offspring, at least through the period of preadolescence. In developing countries, children play a central role in generating economic resources for their parents; resources flow from children to their elders (Goodnow & Collins, 1990; LeVine, 1974).

Another way to make this distinction is to refer to the *instrumental* vs. *affective* roles that children play within families (Elder, 1974). When children fulfill instrumental needs, they carry out tasks necessary for the family's welfare, either by doing domestic chores that would otherwise require compensating a non-family member (e.g. childcare, food production, shelter maintenance) or earning cash income that is contributed to the household. In

the absence of instrumental assignments, children play primarily affective roles; they give and receive affection in a way that is psychologically satisfying for both child and parent (under normal circumstances). LeVine (1977) compares African and American values with respect to these roles. He writes that:

> Among African peoples, for example, parents frequently expect the child to contribute his labor to the domestic productive unit, to give respect to his elders, and—when mature—to support his aging parents. In our society, parents often talk of what they want from their children in terms of affection, enjoyment, and love. (p. 17)

In general, economic conditions influence parenting goals and parents' responses to children's developmental needs (Levine, 1974; 1988). Economic conditions, in turn, are associated with the resource base needed to support child development. For example, in poor societies with high infant mortality and morbidity rates, parents place a much greater emphasis on assuring the physical health and survival of their infants, and subsequently on their children's reproductive capacity at puberty. In wealthy societies with low infant risk rates, parents are less concerned with survival; there is an early emphasis on the attainment of psychological, emotional, and behavioral attributes that lead to economic self-sufficiency and the ability to "maximize other cultural values [such as] morality, prestige, wealth, religious piety, intellectual achievement, personal satisfaction, and self-realization" (LeVine, 1974, p. 230).

The theoretical framework that informs this paper, then, is that cultural influences, including traditional responses to economic conditions, influence heavily the ways in which children are raised and how their relative value is perceived.

A related argument is that parents carry out child rearing practices that are "rational" within specific cultural contexts. An extreme example would be the practice of passive euthanasia when a sick newborn is allowed to die because there are insufficient resources in the family or community to sustain his or her life. Scheper-Hughes' (1987) studies of mothers in northeast Brazil who do not attempt to save their very sick newborns provide examples of such contextually rational behavior. She notes in stark terms, "The alternative fertility strategy in operation throughout much of the poor and non-Western world is more along the lines of: Produce as many offspring as possible, invest selectively, and trust that a few will survive" (p. 146). This strategy can be

viewed as rational, even though by western standards it may appear otherwise.

The theoretical framework that informs this paper, then, is that cultural influences, including traditional responses to economic conditions, influence heavily the ways in which children are raised and how their relative value is perceived. Variations are seen when resource-rich societies are compared to resource-poor ones. These variations become even clearer when a child is born with or acquires a developmental disability. In such cases, the child is clearly less able, perhaps unable, to generate any resources on his or her own that would contribute to the family's well being; in fact, he or she is likely to drain resources that are already attenuated. Decisions to withhold treatment—or conversely to provide extraordinary treatment in order to assure survival and economic value—begin to be understood as rational choices, even when they are interpreted as responses to culturally defined religious or ethical laws.

Historical Factors: Colonization and the Missionary Movement

The primary historical factor that informs the present paper is the effect of colonial occupation on non-western societies, beginning in the 17th century and reaching a zenith in the late 19th century. This time period was marked by the exploitation of human and natural resources by European nations of cultures located in the eastern and southern hemispheres. One result of this exploitation has been the unequal distribution of resources between western and non-western societies. In contemporary terms, this discrepancy is described as a north-south rift, in which countries of the northern hemisphere are characterized as amassing capital as countries in the southern hemisphere experience protracted poverty, even when they may possess the goods necessary for the production of valued capital (such as crude oil, precious minerals, and hardwoods). The unequal distribution of resources is correlated with the incidence of disability. Three-quarters of all disabled people now live in developing countries, and that ratio is expected to increase to four-fifths by the year 2000 (Noble, cited in Nkinyangi & Mbindyo, 1982).

Colonialism brought with it, often via missionaries seeking to convert the "heathens," a number of value systems, governmental policies, and military actions that have affected traditional and evolving beliefs toward people with disabilities. In addition, the effect of natural disasters, continued tribal or ethnic warfare, and the nature of post-colonial governments have contributed to these beliefs. Thus, both foreign and indigenous forces have contributed to traditional and evolving responses to disability. The interplay of these external and internal forces has resulted in a complex array of policies,

programs, and practices that reflect both local values and values that originated in very different sociocultural contexts.

Educational Values

The first colonial legacy to be discussed is the inheritance of a particular educational system, best described as "British," with values related to meritocracy, exclusivity, centralized decision-making, and vocationalism. The concept of meritocracy is particularly important for the present discussion. If we contrast meritocratic educational systems with democratic ones, the former is characterized by selectivity—the most intellectually capable students are identified through a process of competitive examinations and deliberate, homogeneous tracking which begins early in formal schooling. The latter may be characterized by universality—where the goal is to provide equal opportunity to all students, regardless of inherent capacities or social status. Meritocratic models of schooling are often associated with the British educational system (including those schools established in British colonies), while democratic models are associated with (perhaps idealized) versions of the system that has evolved in the United States.

The unequal distribution of resources is correlated with the incidence of disability. Three-quarters of all disabled people now live in developing countries, and that ratio is expected to increase to four-fifths by the year 2000 (Noble, cited in Nkinyangi & Mbindyo, 1982).

The Relation of Social Values to Education. While the colonists were imposing a new form of schooling on their subjects, traditional social values continued to operate. One value dichotomy that has been used to distinguish traditional, agrarian cultures from modern, industrialized ones, is that of ascribed (personal) and achieved (social) attributes. Achieved characteristics are those attained as a result of life experiences (e.g. schooling, economic success, occupational status); ascribed characteristics are those qualities one is born with or into (e.g. gender, family name, genetically determined abilities) (Parsons, 1951). In the modern, western world, greater value is placed on achieved attributes. Our myths tell us that anyone can become president, or a CEO, if she is well educated and develops the right connections. On the other hand, traditional, agrarian societies have usually valued ascribed characteristics related to gender, birth order, social class, clan membership, and physical capacity. For example, first born females have often been subject

to infanticide or neglect in cultures that place a primary value on males, first born or otherwise.

To the extent that this distinction remains valid in developing countries, infants or young children with apparent physical or intellectual disabilities, attributable to poor genetic endowment or to some divine intervention (holy or unholy), may be either devalued or (less often) venerated compared to children with normal characteristics. We can find evidence for such attitudes in societies that practice benign neglect of children born with congenital anomalies, and in societies that actively maim children so they may serve as street beggars in order to contribute to the family income (or where females are circumcised in order to increase their social and economic value; this latter type of disability is neither ascribed nor achieved—rather it is imposed for someone else's economic benefit). In these cultures, genotype and phenotype are more salient than achieved attributes acquired through education and life experience.

Years of colonial occupation and subsequent westernization have led to some assimilation of the values of achievement. Education is seen increasingly as a tool for individual and social development. In this view, academic achievement can supersede whatever physical or genetic limitations a child brings to school. This is the rationale for western models of "compensatory" or "remedial" education. But in some developing societies, the values of compensation and remediation may not be indigenous. In those cases, western values have been overlaid on traditional ones. If these two sets of values are not inherently compatible, the result may be social stress and ambiguity about the relative importance of achieved vs. ascribed characteristics.

The Missionary Movement and "Paternalistic Universals"

Another historical factor bearing on this discussion is the missionary movement that accompanied colonization. The missionary movement brought with it not only the Christian ideals it professed, but the less noble traits of paternalism, chauvinism, and ideological conversion as a requisite for salvation. The "white man's burden" and the "noblesse oblige" that came with that burden created attitudes that devalued indigenous cultures and belief systems. Harlan Lane (1988) writes eloquently about this problem by drawing parallels between present-day attitudes toward people who are deaf and colonial, paternalistic attitudes toward the people of Africa.

> In a paternalistic relation, the benefactors have among other roles that of educators, and they prove to be educators who subscribe to the tabula rasa view; their beneficiaries have no language, culture, institutions—or none worth considering—and the benefactors have the burden of supplying them with

> their own. Thus it was that the civilizing task of the colonizers in Africa required them to supplant the natives' languages, religions, and institutions with those of the European mother country. (p. 10)

Lane identifies a number of "paternalistic universals" that are useful for the present discussion. For example, he compares the traits attributed to Africans in colonial literature—barbaric, insolent, submissive, cunning, child-like, irrational, unintelligent, animalistic, feeble, stunted—with traits attributed to deaf people in professional literature—asocial, disobedient, submissive, naive, poor language, restricted reasoning, hedonistic, immature. In other words, Lane argues, the attitudes of the European colonizers toward their African subjects is analogous to the attitudes of some rehabilitation and special education professionals toward their disabled "clients." The residual attitudes of the colonizers that have been assimilated in developing countries by political leaders, educators, and the general public place native people with disabilities at continuing risk for being the object of paternalistic, oppressive treatment.

An important question is whether those residual attitudes are fading or being reinforced under present conditions. One interpretation is that they are being reinforced as post-colonial, developing countries continue to adopt Anglo and European policies and practices with respect to the treatment of people with disabilities. These practices have historically assumed professional control and client passivity, sometimes described as the "medical model." That is, the dyadic helping relationship is similar to that between the colonizer and the colonized. It may be that the uncritical importation of hierarchical models of treatment will perpetuate restrictive, meritocratic attitudes rather than create more democratic, liberating conditions.

One legacy of the missionary movement is reliance on voluntary, non-governmental services to marginalized groups rather than use of more formal, state-operated and funded services.

Balancing this tendency, however, is the emergence of professional and self-advocacy movements in countries such as India, Kenya, and Nigeria. These movements may be partially attributable to the 1979 United Nations Year of the Child and the 1980-81 International Year of Disabled Persons (Nkinyangi & Mbindyo, 1982). Again, both the positive and negative aspects of the legacy of western influence are evident. While democratic, universal ideals are intrinsic to self-advocacy and full social participation, the danger of corruption is ever-present. Thangavelu (p.c., 1991), writing of the situation in

India, states: "With institutionalisation of partisan politics, the cause of the disabled is widely recognized and advocated, but unfortunately, the current program for the disabled suffers from professional, organizational, and political exploitation by the able ones for purposes of professional advantage and income generation for the advocates through corrupt practices."

Voluntary vs. Governmental Sponsorship of Services

One legacy of the missionary movement is reliance on voluntary, non-governmental services to marginalized groups rather than use of more formal, state-operated and funded services. This reflects the social gospel theology of the 19th century. In general, non-governmental organizations (NGO's) have been successful and have been widely accessible, at least in the urban centers of developing countries. Through local and international charitable organizations such as the World Rehabilitation Fund, and through initiatives sponsored by various United Nations affiliates, a great deal of program development has occurred and been sustained in previously colonized countries. (Perhaps the "white man's burden" has been transformed into the "white man's guilt.")

However, continued reliance on NGO's in developing countries has meant that there has been very little formal, public commitment to services for people with disabilities. Such services have been assumed to be the responsibility of philanthropists and charitable organizations rather than the state.

The debates that have occurred in the United States over special education legislation and the recently enacted Americans with Disabilities Act have led to widespread awareness, if not acceptance, of the fundamental responsibility of the government to improve the lives of people with disabilities. There appears to be a basic constitutional acceptance of this obligation. In countries that have not relied on government leadership and constitutional mandates to assure adequate services, there is no consensus about the value of special education and rehabilitation services. While the United Nations Charter on the Rights of the Disabled is often cited in developing countries as an expression of "international law," it carries no statutory weight. This vacuum of public commitment may make it more likely that negative attitudes toward people who are physically or psychologically impaired are sustained.

Ethnicity and National Boundaries

An additional contextual factor associated with colonization is the on-going civil and guerrilla warfare resulting from the arbitrary geopolitical boundaries drawn at the end of the colonial era and after the first and second

world wars. These boundaries often have not reflected long standing ethnic and tribal territorial divisions. The consequences have been civil strife, unstable governments, and discrimination against tribal or ethnic groups who are not part of the ruling majority.

The major impact of these trends for people with disabilities has been two-fold. First, the civil warfare itself has been a major cause, and in some cases the leading cause, of disability. Adults have become permanently disabled as a result of war injuries, and children have become disabled during military actions and in the aftermath when they discover unexploded munitions or land mines. Second, scarce national resources—human and financial—have been directed toward fighting battles or maintaining control in unstable societies rather than toward the development of the common weal, including the provision of services for people with disabilities.

Natural Resources and Natural Disasters

During the colonial era and since, developing countries have been subjected to the exploitation of natural resources by western (and more recently Japanese) governments and corporations. This has led to the exportation of valuable goods, and often the exportation of capital, reducing the amount of capital available for internal development. One result has been underdeveloped infrastructures for the support of health, education, and social services, and the training and support of an adequate supply of professionals.

Exacerbating the loss of capital is the fact that developing countries experience natural disasters at a higher rate than other parts of the world, and are less able to cope with conditions of famine, drought, or flood because of the severity of these conditions and the lack of infrastructure necessary to overcome the results of disaster. The consequences are both a further drain on national resources needed for social services and an increase in the number of children and adults who are disabled due to injury, starvation, and illness.

To summarize, a number of contextual factors—the adoption of a meritocratic educational system, the effect of paternalistic attitudes, the role of NGO's vs. government-sponsored agencies, ethnic/tribal conflict, and the drain of natural resources from countries that experience high rates of natural disasters—provide a framework for analyzing attitudes toward people with disabilities in developing countries. It is necessary to consider these historical conditions before attempting to understand present and evolving belief systems about the cause and consequence of disability. Such an understanding, in turn, is a prerequisite for designing health, education, and social service systems that take into account indigenous values while incorporating effective, modern treatment technologies.

Based on an analysis of the letters, articles, and documents sent to us by nearly 40 respondents, it is possible to propose six emergent themes useful for subsequent investigation on the matter of changing belief systems affecting people with disabilities.

A Framework for Examining Sociocultural Variables

With these historical factors in mind, we now turn to the results of the review of materials made available through our correspondence with experts in a number of developing countries. Based on an analysis of the letters, articles, and documents sent to us by nearly 40 respondents, it is possible to propose six emergent themes useful for subsequent investigation on the matter of changing belief systems affecting people with disabilities. Each theme will be briefly elaborated by posing a number of empirical questions that can serve to guide more thorough subsequent analysis. Essentially, I hope to lay the groundwork for the kind of inquiry that Groce (1990) and others have recently called for. After identifying the six themes, examples from three developing countries will be offered to illustrate their salience.

1.0 Cultural Values

There were a number of values expressed in the materials we collected that reflect basic cultural belief systems. These values emerged as seven dichotomous variables, with gradations possible between the two polar descriptors. The six factors are:

1.1 Egalitarianism vs. Competition

To what extent does a given society value equal opportunity and outcomes for its citizens, vs. individual achievement through successful competition?

1.2 Conformity vs. diversity

To what extent does a given society value behavioral and intellectual conformity vs. expression of individual differences?

1.3 Exclusion vs. inclusion

To what extent does a given society value exclusive, independent lifestyles and action vs. inclusive, communal lifestyles and action?

1.4 Volunteerism vs. professionalism

To what extent does a given society value volunteer effort through informal, charitable organizations vs. formal, professional treatment sponsored by private or public social welfare agencies?

1.5 Charity vs. entitlement

To what extent does a given society conceive of the treatment of people with disabilities as an act of charity vs. an entitlement for which all citizens are equally eligible?

1.6 Fatalism vs. secularism

To what extent does a given society support beliefs related to fatalistic acceptance of disability vs. secular, scientific explanations of disability and its treatment?

2.0 Attribution Theories

Attribution theories have to do with explanations of the cause of disability. Here there were three dichotomous variables and a more general theme that requires further analysis:

2.1 Blessing vs. punishment

To what extent is the presence of a disability interpreted as a sacred blessing vs. a punishment for some moral digression on the part of the individual or family?

2.2 Divine intervention vs. the work of a sorcerer

Related to the previous variable, to what extent is the cause of a disability seen as the work of benevolent god(s) vs. the work of the devil or an evil spirit?

2.3 Biological vs. environmental factors

To what extent is the presence of a disability attributed to biogenetic factors vs. ecological or environmental factors?

2.4 Ontogeny and phylogeny

To what extent is a disability interpreted as an expression of a lower, less evolved life form?

3.0 Attitudinal Responses

While the first two themes were concerned with underlying values and belief systems, it was also possible to identify material that reflects the expression of those values and beliefs in the form of overt behavior or written materials, illustrating policies and practices based on particular values. These were clustered as attitudinal responses.

3.1 Fear vs. veneration

To what extent do family members and others respond to an individual who is disabled with the kind of fear associated with the profane, or is there a response of veneration, stemming from an interpretation of sacredness?

3.2 Stigma vs. acceptance

To what extent are individuals with disabilities treated as objects of horror or deviance, and ostracized, ridiculed or segregated; or are they treated as fully human beings who are entitled to live in close proximity and in social equality with others?

3.3 Deprivation vs. intervention

To what extent is the normative response to people with disabilities one of deprivation of fundamental rights (to treatment, to free movement, to free association, to shelter and food) or one of intervention, intended to improve the lot of the individual through direct care and support? How are these responses mediated by the assumed prognosis for the individual (i.e. whether the person will become a "contributing" member of the society; whether the person will live for an extended period of time)?

3.4 Ambiguity

- Are varying social responses seen toward people with disabilities within a particular culture that may indicate ambiguity, changing attitudes, or changing prognoses related to the use of new technologies or new service delivery systems?
- Do attitudes vary with the disabled individual's age, ethnicity, gender, religion, birth order, or socioeconomic status?

3.5 Functional roles

- Are individuals with disabilities expected to fulfill socially and economically valued functional roles in order to gain acceptance or validation?
- What kinds of roles are required to achieve acceptance (e.g. begging for alms, menial labor, or semiskilled and skilled work)?

3.6 Distance and frequency of contact

Does close physical proximity and increased contact result in a familiarity that is associated with

tolerance, acceptance, and personal knowledge of an individual that helps to overcome the apparent physical or cognitive differences?

Do social systems based on traditional, familial relationships, that are characterized by frequent contact and interdependence, support more acceptance than complex, urbanized settings that value social distance and formal exchanges?

3.7 Locus of culpability

- When a disability is thought to be the "fault" of the individual, does that lead to more negative attitudes than when conditions are thought to be caused by factors external to the individual?
- If parents believe they have caused the disability through some act prior to the birth of the child (of either omission or commission), do they experience guilt or shame? Do parents direct those feelings of culpability to others (relatives, neighbors, enemies, priests) and blame them for creating the condition through either direct or divine means?

4.0 Institutional Effects

The previously listed cultural values, attribution beliefs, and attitudinal responses influence, and in turn are influenced by, the institutional structures potentially available to people with disabilities. These structures include schools, community programs, and the broader economic contexts which produce income and support formal services.

4.1 School attendance rates

Are school attendance rates of children and youth with disabilities a measure of social attitudes, or perhaps a cause of changing attitudes?

4.2 Congruence of program design with indigenous values

Are formal treatment programs designed to reflect local customs and beliefs, or is there incongruity between such programs (especially those modeled on western practices) and local traditions?

4.3 Industrial vs. agrarian economy

To what extent does a given society rely on industrial models of production vs. agrarian ones, and how do these different models affect belief systems? Do industrial economies create greater discontinuities between the form of treatment provided and tradi-

tional belief systems than agrarian economies?

4.4 Economic system for distribution of goods and services

- Do traditional systems of exchange (barter, labor, sharing common property) support or hinder the acceptance of individuals with disabilities?
- Will the tendency toward capitalism in some developing countries affect social attitudes, or affect the goals and design of treatment services?

4.5 Formal definitions of disability

Do formal, codified definitions of disability exist; and if so, how do they reflect and affect social attitudes? What has been the rationale for adopting formal definitions in societies where none existed previously?

4.6 Self-contained programs

Does reliance on segregated, self-contained educational or rehabilitation programs improve or hinder the process of social acceptance in developing countries?

4.7 Role of traditional healing practices

Do individuals with disabilities rely on traditional systems of health care (spiritual, herbal, holistic) or are they more likely to be referred to modern, technology-based treatment? To what extent do the two systems interrelate? Do individuals with disabilities use different treatment systems than those without disabilities?

4.8 Institutional vs. community-based care

Is the shift from institutional to community-based care that is occurring in some developing countries affecting attitudes toward individuals with disabilities? Are some categories of disability more likely to be treated in institutional facilities than in small, community programs?

4.9 Cost of services and source of payment

- To what extent are the costs of services distributed across society in general, or is the assessment of costs limited to those who use habilitative services?
- Are those individuals who are incapable of paying the full cost of treatment less likely to be served?

5.0 Adaptability and Change in Belief Systems

Of central importance to all of these factors is the degree and pace of

change that is occurring, the reason for such change, and the outcomes. By definition, developing countries are undergoing significant social, economic, and political transformations. These will inevitably impact people with disabilities, either directly through new policies and programs that result from institutional changes, or indirectly through changes in attitudes and beliefs that affect individual and social responses to the phenomenon of disability.

5.1 Effects of relocation

As indigenous groups are relocated due to economic disruption (e.g. destruction of the rain forests) or to civil strife (e.g. war, famine), do explanations about the cause of disability and social attitudes toward disability change in order to adapt to the circumstances and norms of the new environment?

5.2 Role of professional and self-advocacy efforts

Have movements toward democracy in developing societies been associated with increased advocacy efforts, both by professionals and by people with disabilities and their relatives? Have these efforts been non-categorical or defined by disability groups? Have these movements been influenced by those that have developed in western cultures over the past 20 years?

5.3 Value of "independence"

Is the purpose of education and rehabilitation "independent, individual functioning" in the western sense, or are the traditional values of community and interdependence being sustained?

5.4 Emulation of western models

To what extent are new treatment approaches an attempt to consciously emulate western, technological models? What are the consequences of this process where it is occurring? Are the same patterns of policy and program development occurring?

6.0 Nature of the Disability

We have learned in our own culture that the nature of a particular individual's disability has an important effect on how others respond. Cognitive disabilities in our culture lead to dehumanizing attitudes, and the "personhood" of the individual may be called into question (Cohen, 1990). Physical disabilities may lead to social isolation and ridicule. In other, more traditional cultures, similar patterns may occur.

6.1 Functional impairment

Are attitudes toward individuals with disabilities

affected by the degree to which an impairment affects functional capacity, or are attitudes independent of functional impairment? Are various physical or intellectual functions valued differentially in diverse developing countries?

6.2 Type and cause of disability

- Are various types of disability interpreted differently with respect to attribution and outcome?
- Do varying interpretations of cause and outcome lead to varying social attitudes?

The six themes—cultural values, attribution theories, attitudinal responses, institutional effects, adaptability and change in belief systems, and the nature of the disability—and the analytic questions associated with each theme, emerged from a review of the materials collected from the specialists described earlier. The themes are meant to serve as tools that can help us to begin to answer the four questions listed at the beginning of this essay. However, the themes and questions are only initial interpretations that must be critically tested in actual contexts by individuals who live and work in developing countries. The following examples suggest ways to illustrate the themes in order to assess their usefulness.

Attribution, Integration, and Community Relations: Examples from Zaire, Kenya, and Thailand

Zaire: Three Types of Children

Devlieger (1989) has provided a rich description of responses to childhood disability in the Songye tribe, which populates the East Kesai region of Zaire. The Songye classify children born with physical anomalies into three groups—ceremonial children (baana mishinga), miserable children (baana ba malwa), and faulty children (baana ba bilema). Each of these categories illustrates varying interpretations of the causes and outcomes of disability.

Ceremonial children possess some irregularity or exceptionality at birth. The name given to the child reflects his or her particular difference. There are five specific conditions that result in a child being viewed as ceremonial. These include being a twin, having teeth already erupted, having the umbilical cord wrapped around the neck, being born with a hand touching the cheek, and being born via breech delivery. Three of these five conditions are associated with developmental risk in our own culture, while early tooth eruption and the placement of a hand on the cheek would be viewed as benign. Children born with any of these conditions are granted elevated status

in the tribe, and treated accordingly.

Miserable children are those born with albinism, dwarfism, or hydrocephaly. These children are viewed as supernatural, not as human beings, and are believed to be in contact with the anti-world of sorcerers prior to their birth. They will return to that world in a short time. Their purpose in coming to the earth is to die, rather than to live. Thus, they are assigned an inferior status in the tribe, and little is done to make their lives comfortable or meaningful.

Faulty children fall somewhere in between the first two groups. They are children who have some obvious physical anomaly at birth that does not fall into one of the categories above. For example, a child born with a club foot is viewed as deviant, but her status is ambiguous. She is clearly seen as human, and she is not marginalized by the tribe. She also possesses spiritual attributes that are interpreted by the family as signs of reincarnation. The physical anomaly is believed to be connected to the history of an ancestor. In the case of a club foot, the anomaly is thought to be the result of an ancestor being buried in a coffin that was too small. The means of "transmittal" occurs if a pregnant woman is present at the ancestor's burial, and if there was a close link between the deceased and one of the newborn's parents. The transmittal of the defect does not take place in all cases—only if a family member has not obeyed the cultural norms. The most common sins that bring this kind of retribution are adultery and theft. Thus, although the family is punished for this transgression, the status of the child is not affected—he or she is seen as "faulty" but neither blessed nor inhuman.

Other attributions identified by Devlieger (1989) include payment of an inadequate or poorly distributed dowry, jealousy of another family's wealth, and quarrels between the pregnant woman and other family members. In any case, attributions are associated with the type and degree of disabling condition, and these, in turn, affect the resulting social status of the child.

Nicholls (1992) provides corroborating examples from the Yoruba of Nigeria. The Yoruba believe that albinism, blindness, and physical impairments are due to divine intervention. Obatala is the god who creates the form of living things. Beier (1969, cited in Nicholls), writes,

> The creation story of the Yorubas says that Obatala created human beings out of clay. . . One day, however, Obatala went drinking. That day he created albinos, cripples (sic) and blind people. In memory of that day, the worshipers of the Orisa (deity) are forbidden to drink palm wine; and afflicted people are considered to be especially sacred to the god and they are given positions of some importance in his shrines. . . Not only

> are they the creations of the same god but they are his own special favorites, with a special place in his form of worship which no one else can fill. (p. 12)

Kenya: The Interplay of Social Values and Economics

Kenya has traditionally relied on institutional, congregate care for people with disabilities. By the end of the 1970's, a "small home movement" to create more community-based facilities was begun by the Catholic dioceses. However, federal officials were described as "cynical, if not down right hostile" (Nkinyangi & Mbindyo, 1982, p. 31) to private sponsorship.

> There are those officials . . . not used to innovation or alternative approaches to doing things, unless of course the innovations and alternative approaches have been given the blessing of foreign "experts." (Nkinyangi & Mbindyo, 1982, p. 31)

The contemporary state of affairs in Kenya was revealed in a 1981 survey of 1717 adults with disabilities. The survey results indicated a relationship between reliance on institutional care and the ability to pay. (The survey also found that very few of the respondents held traditional views about attribution. Two percent believed they were disabled because they had been "bewitched." The remainder could either cite a specific disease or trauma [78%] or did not know the cause [18%].) A large majority (between 60 and 70 percent) of the respondents had no formal schooling or rehabilitation, due to lack of money to pay for such services and lack of parental support for these forms of intervention. One-fifth of the respondents had been unable to apply for admission to rehabilitative institutions because of their inability to pay, and one-quarter of those who were enrolled were subsequently expelled because they could not keep up their payments (Nkinyangi & Mbindyo, 1982).

Nkinyangi and Mbindyo (1982, p. 26) also noted that, "Institutions turned away aspirants who had anything but the most minimal disabilities." Among the survey respondents, 13.2% indicated they had been refused admission to institutions because their disabilities were too severe. Others had been admitted but were later sent away because of "poor performance" or the severity of their disability. One reason for these exclusive practices is lack of government funding, resulting in the need to charge fees and only serve the least disabled. Even for those admitted, the quality of care is far from adequate. The institutions are characterized as having "poor facilities, crowding, bad diet, and a low standard of hygiene" (p. 27).

Community life for people with disabilities is also subject to economic and social factors. Nkinyangi and Mbindyo (1982) found a general pattern of

employer resistance to hiring people with disabilities and low expectations for the abilities of such people. As in other parts of the world, there appeared to be little correspondence between existing vocational training curricula and the actual demands of available jobs. Vocational programs have emphasized the traditional jobs held by people with disabilities—tailoring and leather-work—in spite of the disappearance of these jobs due to the changing economy and the desire of disabled people to enter clerical and domestic positions.

As in other developing nations, begging has been an historical means of subsistence for those with disabilities. A subset of Nkinyangi and Mbindyo's survey sample (n=68) were beggars. The majority (94%) of these had only turned to begging after failing to find other means of earning a living, and sixty percent of the group had been begging for more than 10 years, mostly in urban settings. Begging is relatively lucrative for people with disabilities, compared to the average wages earned by other disabled people. Typically, disabled beggars earned from 50 to 100 percent more than their non-begging peers on a daily basis. Attempts to find other, more socially valued, occupations, are often met with failure.

Nkinyangi and Mbindyo tell the story of KK, a street beggar who was born "seriously crippled from below the waist" (p. 40). As an adult, he had a wife and six children who lived in his native village. His family depended entirely on KK's earnings. In an interview, KK discussed the reality of being an adult with a disability, and the difficulty of becoming economically self-sufficient:

> You see, in the Kikuyu custom one becomes mature after circumcision. Whether you are a cripple like me or not, after circumcision you are considered to be ripe for self-independence, indeed, to have your own ways, family, and property. This is not difficult for a person from a strong clan. The clan would always pay to get you a wife. But you see, I came from perhaps the poorest clan in our area. Shortly after circumcision I learned that I was becoming a big burden to the few relatives, friends, and neighbors. For a long time I was very worried about what I would do. Then friends advised me that if I came to Nairobi I would meet many other cripples who depend entirely on begging for their life. There I would not feel ashamed begging. So I came to Nairobi in 1965 and started the career of begging on the streets. It was a hard change but soon I became happier here than I was at home. After begging for some time I was able to save some little money and I decided to open a vegetable kiosk. I gave up very soon as it was very difficult to get vegetables for sale from the retail market. I tried "Mali Rashi" (selling second-hand clothes) but almost as quickly gave it up for lack of capital. I went back to the streets very frustrated. (p.

41)

The important lesson here, at least from a western perspective, is the need to design vocational programs that prepare people with disabilities to move into competitive and socially valued occupations. When the economic incentives are too weak to allow people to move into such roles, when the cost of rehabilitative services is high and largely borne by the recipients of those services, and when services are not able to meet the needs of more severely disabled people, traditional social roles and officially sanctioned practices of exclusion will be sustained. This lesson certainly has implications for many cultures, not just those we refer to as developing.

Thailand: Parallel vs. Integrated Systems

As noted earlier, many services for people with disabilities in developing countries are sponsored by charitable organizations, including those that reflect a history of missionary activity. In Thailand, services for people who are blind have been developed by the Dark and Light Foundation of the Netherlands (it is impossible not to note the racial irony of the name). A local group, the Christian Foundation for the Blind in Thailand, has worked to establish community-based rehabilitation programs, based on agricultural training. The programs consist of small, residential compounds located throughout the country. In a recent report from the Christian Foundation to its sponsor, the Dark and Light Foundation, the problem of embedding CBR programs within indigenous contexts is apparent:

> We now find there is a need to construct fencing around the Korat compound [the CBR facility] to keep out stray animals, mostly water buffalo, who use the grounds as pasture land. In addition, many local villagers use the compound as a short-cut walkway to reach their homes from the main road. This creates a major security problem. In view of our plan to develop 3 or 4 acres of land for students to have agricultural products, the need for fencing becomes more and more acute and imperative. (Punongong, p.c.)

This example may be interpreted as indicative of the problem of creating community-based facilities if there is not an explicit commitment to integrating the facility fully into the local culture. Here, the desire seems to be to create a *parallel* facility that co-exists with the local community, but is not a part of it. The metaphorical and literal meaning of the fence is that the facility wishes to be self-contained rather than enmeshed in the life of the villagers. Another solution to the problem might be to develop *joint* agricultural projects with the villagers that would ultimately lead to more natural and sustainable forms of social integration and economic development. This example is reminiscent of western attempts to deinstitutionalize people with disabilities by placing

them in community residences that end up looking like and being perceived as mini-institutions.

These examples serve to illustrate some of the themes that arose from the materials provided by our international colleagues. The six categories—cultural values, attribution theories, attitudinal responses, institutional effects, adaptability and change in belief systems, and nature of the disability—are reflected to some degree in each culture described. We have other data from Nepal, Pakistan, India, Indonesia, and Malaysia that support the argument that these categories include the major factors to be considered when seeking to understand beliefs and attitudes and how they might be changing in particular developing societies.

It is also possible to see reflected in these stories the historical factors summarized earlier. For example, indigenous beliefs about attribution are interacting with more modern explanations; services are viewed as the responsibility of charitable organizations rather than government, resulting in less than universal coverage; economic conditions affect familial and societal responses to disability, and influence the goals of treatment; and, power relations between people with disabilities and professional helpers mirror colonial relations between subjects and government officials.

Conclusion

The purpose of this paper has been to identify key variables that must be addressed in order to understand the changing nature of beliefs about disability in developing societies. There are surely lessons to be learned in such an inquiry—lessons that can guide practices in developed countries seeking to restore more humane and connected forms of treatment, and that can guide emerging societies desiring to provide more effective and comprehensive support within traditional contexts. While the claim can be made that contemporary western policies and practices have benefited people with disabilities, the leap to assuming that importing those policies and practices into non-western societies is inherently right should be subjected to critical and deliberate analysis.

Such an analysis must begin with a deep understanding of the societies in which western practices are to be integrated. Because the countries themselves are undergoing rapid change, it is logical to assume that beliefs about disability are also changing. That assumption must be tested, and if it proves to be correct, we must then ask how those beliefs and resulting attitudes are changing, why, and what the consequences are. At that point, we will be able to come full circle and ask how we might learn something about ourselves and our own practices in order to enhance the lives of people with

disability in all societies. When the process of designing and improving services is seen as a reciprocal transaction that is benefited when diverse cultures and perspectives are joined, then the traditional traps of noblesse oblige and conversion will be replaced by the higher principles of collaboration and common cause.

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CHAPTER TWO
An Examination of Some Traditional African Attitudes Towards Disability

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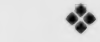

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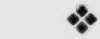

...there is now a body of opinion that suggests that traditional African societies are in many ways more "human" and more "humane" than modern industrial societies.

Africa's potential contributions to the intellectual market places of world thought have been generally overlooked or discredited. Instead of recognizing that traditional African ideologies contain real wisdom, negative views of traditional culture have prevailed and an idea promoted that African cultures are more "primitive" and "barbaric" than so-called "civilized" cultures. In recent years this bias has been changing and scholarly areas such as ethnoscience and ethnomedicine have emerged which look at traditional cultures as a source of valuable knowledge (see, for example, Brokensha, Warren, and Werber 1980). In addition, there is now a body of opinion that suggests that traditional African societies are in many ways more "human" and more "humane" than modern industrial societies. French anthropologist, Jacques Maquet (1972), for example, argues that there is less stress, anxiety, and insecurity in traditional African societies. He states, "African societies ... are much better than industrial societies at organizing human relationships so as to reduce tensions and anxieties." An example that springs to mind is that

Africans find the idea of abandoning aged relatives in old peoples homes morally unacceptable. In traditional Africa the elders are treasured and respected (Ndege and Nicholls 1990:17).

How does the social orientation of traditional Africa affect attitudes towards disability and how have these attitudes been portrayed to the outside world? Although research in this area is scanty, there has been an observable tendency to reduce African ideas about disability to a few hackneyed scenarios whereby disability is seen either as a result of witchcraft, i.e. ill intent directed from a human agency by supernatural means, or as a form of divine retribution visited on a negligent individual for failing to observe a religious code or for breaking a taboo. Vengeful ancestors are most often depicted as the culprits in the latter scenario. Anyatunwa (1977) maintains that a belief exists among the Ngwa Igbo that Albinos and the physically handicapped are thought to have sinned in their previous lives (the Igbo, like the Igede and many other African ethnic groups believe in reincarnation). Writing of the Yoruba, Adeoke (1977) argues that many disabilities are perceived to be the work of wizards as punishment of offenses. He instances blindness, which is perceived as being caused by black magic as a result of jealousy. According to Adeoke, epilepsy is thought to be caused by the presence of lizard like creatures in the stomach and is believed to be contagious. Adams (1949) conducted a survey of attitudes towards disease and disability among medical trainees in Rhodesia (now Zimbabwe). He relates that cerebral palsy was seen as being caused by either witchcraft, spirits, or a failure to observe a taboo. Blindness was attributed to witchcraft; Leprosy was perceived as being the result of witchcraft or spirits or of natural causes.

Although not disputing that in some cases these scenarios apply, this paper attempts to counter the standard stereotypes. In some cases there is a need to examine the background and motives of those who report on traditional beliefs to discover whether or not they may be subject to conscious or unconscious biases. Whether, for example, they are non-African, or if they are African whether they are the products of mission schools or harbor ambivalent attitudes towards traditional culture. Walker (1978:21) points out that diversification in perception of the disabled exist in Africa. Accordingly, alongside negative reports, more positive examples can be found. Field (1937), for instance, notes that the Ga, a group from the Accra region of Ghana, treated the feeble minded with awe. They believed the retarded to be the reincarnation of a deity. Hence they were treated with kindness, gentleness, and patience. Walker (1978:20-21) states:

Among the Chagga, an East African group, the crippled were perceived as satisfying evil spirits, thus insuring normality in others. Hence, care was taken not to harm the physically handicapped. Among the citizens of Benin (formerly Dahomey in West Africa) constables were selected from those with

obvious physical handicaps. Children born with anomalies in Benin were felt to be under the guardianship of special supernatural agents. These children were well received since they were believed to bring good luck.

My experience in rural Igede in Nigeria's Benue State, where traditional beliefs are still somewhat operative, is not so much of a mystical or superstitious population, but rather of a pragmatic, matter-of-fact people.

An example of sensitivity to people with disabilities is found among the Dan people of Liberia. A major function of masks in Africa is to communicate social mores. The Dan have a range of masks that represent the symptoms of diseases and deformities. For example, a mask afflicted with a tumor of the jaw performs an awkward crippled dance punctuated by comic gestures. However, spectators who acknowledge this deformity through laughter, revulsion, or by any other means, are fined. According to Hinckley (1987) this mask "cautions people not to ridicule deformed people."

This essay adopts a Pan-African approach and compares the beliefs and behaviors of disparate ethnic groups including the Igede, Igbo, and Yoruba of Nigeria, and the Ndembu of Zambia. It is not suggested that Africans are homogenous ethnically or racially, clearly they are not, nevertheless, parallels can be found in areas of ideology, world view, and sociocultural mores. This essay explores Igede notions of *Ebih*, and *Apuruja*, Ancestral Retribution in general, Healing Rituals of the Ndembu of Zambia, and conceptualizations of the Yoruba relative to *Obotala*, and *Abiku*. The discussion of Ndembu Healing Rituals, the *Obatala* cult, and *Abiku* children in particular suggests that these ideas contain real insights relative to the psychoanalytic method, the place that people with disabilities occupy in society, and the education and socialization of exceptional and special children.

In colonial times the Igede (formerly known as Egede), who are located in the Oju Local Government Area on the southern edge of Nigeria's Benue State, were grouped for administrative purposes with the Idoma, their neighbors to the northwest. In 1976, Oju Local Government Area attained its own divisional status. While there is some cultural overlapping between the Igede, and neighboring Idoma, Tiv, and Igbo ethnic groups, the Igede's history, language, and culture are distinct. I studied the expressive culture of the Igede during my tenure at Ahmadu Bello University in Kaduna State, Nigeria. Although my primary focus was on music and dance and the pedagogical methods by which children develop musical skills (Nicholls 1984;

1992), I came to have a working knowledge of Igede religious beliefs and their world view, including concepts of "self" and attitudes toward ill health and physical and mental impairments.

My experience in rural Igede in Nigeria's Benue State, where traditional beliefs are still somewhat operative, is not so much of a mystical or superstitious population, but rather of a pragmatic, matter-of-fact people. This comes out in the lyrics of an Igede song which makes reference to the embarrassment one might feel if one commits a verbal *faux pas* when in the presence of a person with a disability. If one, for example, asked a blind friend, "Can you come and *see* me on Wednesday?" A song of the Iboma ensemble includes the advice:

If a goitrous person is around, you do not describe the gourd. If a dwarf is around, you do not describe a bantam chicken (Ranung 1973).

...the aim of this essay is to differentiate between* pragmatic spirituality *that reflects knowledge and utility, and* blind superstition *which is in bondage to ignorance.

I first came to know the Igede through an Igede friend of mine, a tailor who was forced to abandon his trade in Minna town in Niger State and return to his village when he lost an arm in an accident. A cousin of his had a club foot, while his sister's mother-in-law became blind after walking into a protruding stick during the dark of night. I never heard any discussion of these impairments being attributed to either punishment from the gods or the result of witchcraft. Igede people traditionally differentiated between those impairments that occur as part of living experience—the result of accidents, catastrophic illness, or loss of function due to ageing—and impairments that result from severe birth defects. They were notably more tolerant of the former than of the latter. In Igede society, as elsewhere in southern Nigeria, people who become disabled as a result of accidents or illness become wards of the extended family system until such a time that they are able to regain their independence. The family's attitudes can be compared to Garza's (1986) description of the attitudes of Hispanic families, which he describes as protective, nurturing, and sympathetic. Garza argues that the protective attitudes of some Hispanic families can stifle independence and self-sufficiency. I will add that my friend the former tailor remained in the village and is employed by the Local Government offices, his cousin's crippled

condition did not prevent him from succeeding as a student, while the blind mother-in-law pursued a career as a traditional singer and is in demand in that capacity.

On the face of it the Igede would appear to fit standard stereotypes of Africans. In his paper "Indigenous Igede Religion," Uko (1988:36) states, "It is not an exaggeration to say that in traditional Igede, religion is life and life religion. They engage religion in whatever they do—whether it be farming, fishing or hunting, drinking, eating or traveling." Yet this notion of an all pervasive religiosity would seem to be an overgeneralization. For example, the Igede were traditionally known as iron workers. Talbot (1926: III, 927-928) refers to Igede (Egede) as one of the main sources of iron for the Ogoja region (in what is now Cross River State). Armstrong (1955:140) confirms that "the Egede hills" were an important center of iron smelting. Yet, neither the Igede nor the Idoma ritualize the use of iron to any great extent. For example, there is no "god of iron" equivalent to Ogun of the Yoruba in their belief system. However, it cannot be denied that historically the Igede had a religious frame of reference. Instead the aim of this essay is to differentiate between *pragmatic spirituality* that reflects knowledge and utility, and *blind superstition* which is in bondage to ignorance. In this sense the rural Igede can be seen to act rationally in the pursuit of self-interest. The essential pragmatism of Africans finds support among anthropologists. For example, Evans-Pritchard (1970:88) argues that they "are for the most part interested in practical affairs, which they conduct in an empirical manner," while Douglas (1966:89) says of Africans, "It is a practical interest in living and not academic interest in metaphysics which has produced ...[their] beliefs."

Hinckley (1987) argues that "in contrast with western science, which casts knowledge in terms of an impersonal, objective world, African traditional thought assumes a personal, subjective universe. Social solidarity is a primary value and Africans tend to see a correlation between illness and social distance. Cures are frequently, therefore, a matter of bringing the person back to 'right relationships' with ancestors, parents, neighbors, spouses or children." According to Walker (1978:43), "When illness or disability occur, the family generally searches for the reason for the presence of such a disaster. An individual may break a taboo unintentionally; he may not even have been aware of the offense until he is told of it." Oga (1988:54-55) provides an insight regarding the Igede view relative to such ideas:

> Many ailments are associated with one god or the other or even sins committed. Thus unless reconciliations or restitutions or compensations, or appeasements are done, herbs become useless in treatment... Where moral sins are committed by men or women, the whole family has to assemble to pronounce the sick one forgiven before herbs could work. Good examples of

> sickness resulting from moral sin are when a baby is sick or where an expectant mother's labor is over prolonged or where a man is bitten by a snake.... *Yet there are many normal cases of illness that respond very well to concoctions without reference to gods or sins, such cases as malaria, hernia, toothache, diarrhoea, backache, etc.* (italics added).

Pappoe (1973) cautions against assuming homogeneity of African attitudes toward disease. Many surveys of African concepts of disability and illness do not give respondents ample opportunity to identify natural processes as the genesis of these conditions. Many Africans do attribute disease to natural origins. Some see a combination of both natural and supernatural etiology (Dodu 1975; Twumasi 1975). In general, it is believed that natural causes are remediated by either scientific or traditional (herbal) medicines. This reasoning demonstrates an essential, and typically African, dualism between supernatural and natural causes of disease. Discussing the ideas of Fiscian (1972) who feels that significant differences in theories concerning disease causality between African and Western man are a matter of degree, not kind, Walker (1978:39) emphasizes that "concepts of supernatural causation of disease are not unique to Africa. These concepts have persisted in Europe, Asia and America." She states:

> Mankind is conceptually dualistic. Most superstitious beliefs do in fact possess a logical and an internal consistency of their own and are not any less logical than explanations in terms of destiny, fate or the Christian God. As a result of the dual nature of man's thinking, even when natural causes for disability and illness are recognized, humans, across cultures, combine efforts to maintain biological stability with attempts to appease the supernatural (1978:40).

Whether or not mankind is "conceptually dualistic," Africans certainly are (see Nicholls 1992 for a discussion of "holism," "pluralism," and "dualism" in African conceptual modes). In his study of the Fang of Gabon, Fernandez (1966:54) observes, "The Fang not only live easily with contradictions; they cannot live without them." Weldon Smith, in his article "African Pragmatism" argues that "African pragmatism is a way of describing how a profound understanding of life's oppositions is formed into working solutions that hold contradictions together and thus are life sustaining" (1978:75). Amidst this debate one thing seems to be clear, responses are not monolithic and differ according to individual interpretation and mindset. This is especially true of the modern era where traditional attitudes are becoming diffused with modern ideas.

Concept of Self

Philosophically, the Igede conceptualize two worlds: *Ijalehe*—the abode of the living—comprises the visible world of tangible, physical matter; while *Ijaleguu*—the abode of spirits—consists of the invisible world of ethereal, spiritual energy. They believe that humans are made up of elements from both worlds. Agocha (1988:14) states that "*Oleguu* (the spirit or soul) is an element of *Ijaleguu* while *Inyiro* (the body) is an element of *Ijalehe*." For the Igede, the genesis of man's essential being is *Oleguu*, as Uko (1988:36) states, "Man ...is made up of body and spirit but by far the greater part of man is made up of the spirit." Although in traditional Igede society, the integrated development of a sound *Inyiro* and a sound *Oleguu* is an ideal, a sound *Oleguu* is the more highly valued of the two. Compare this notion to a statement of Rick Creech (1992), a nonverbal, quadriplegic American: "Only when people understand that disabilities diminish only what is physical and do not diminish the personal spirit, only then will they accept persons with disabilities as whole and complete." According to Agocha (1988:15), Igede tradition is more tolerant of a deformed *Inyiro* than it is of a deformed *Oleguu*. He states, "An Igede man, no matter how sound in body, whose *Oleguu* is deformed is *Ukpilochi*, an uncultured, almost worthless animal." Although Agocha does not define *Ukpilochi*, in Igede terms a deformed spirit is unlikely to refer simply to mental illness. It more likely refers to an individual possessing negative social attitudes; avaricious, lazy, covetous, or with a propensity for evil.

A discussion of values among the Igede, as with other peoples of southeastern Nigeria, must begin with an examination of ancestral beliefs, for ethical standards, moral judgements, and aesthetic principles derive from the ancestors and ultimately the earth. In traditional Africa an individual's primary responsibility is to his kin. This includes both lineage ancestors and those yet to be born. The African did not "worship" the ancestors as we understand the term, but in order to insure stability in his everyday life he had an obligation to maintain a harmonious relationship with them. This was achieved through libations and prayers and by upholding the values and traditions of the community.

The Igede concept of the ancestors (*Aleguu*) and their relationship to the "earth" or "land" (*efi*) is complex. Because in Africa, corpses are invariably buried, the tribal ancestors merge with the spirit of the earth. The embracive term for "ancestors" in Igede is *Aleguu-Ale-efi* which signifies the myriads of psyches of all those who have lived and died and are interned in the earth—the corporate body en masse (note that *Aleguu*, the plural of *Oleguu*—spirit, is combined with *efi*—earth, literally "spirits of the earth"). For the southeastern Nigerian, the earth is the source of morality and *Obe Oleji* (the Igede earth

god) is linked to humans through the medium of the ancestors. Ilogu (1974:22) says of the Igbo, "All the codes of morality are ...sanctioned by the earth goddess *Ala*, and communicated from her by the dead ancestors *Ndichie or Ndebunze* to the community." Willis (1989:63) maintains that "in the Igbo view, morality and beauty is connected. The Igbo believe that whatever is normal, natural, and life-sustaining must have been sanctioned by the earth deity and is therefore ethical, good, and by extension beautiful." In addition, "Ala is ...seen as the wellspring for creation and creativity in a more general sense."

Ebih

The Igede maintain that the natural order of creation is pure and this is contrasted to disorder and impurity which is considered dangerous to society. Whereas the earth and ancestors embody order and symmetry, the Igede concept of *Ebih*, denotes those aberrations which violate the natural order of things. This covers a range of unnatural events and behaviors. In the realm of physical conditions, Idikwu (1976:34) attributes three circumstances to *Ebih*. The third of these indicates babies born with severe birth defects:

- A swollen belly, or feet and legs [possibly dropsy or elephantiasis].
- Woman under pregnancy who has been under labor of child birth but dies without first giving birth to the child.
- A child which is born with incomplete limbs or any other visible part of the body incomplete, e.g. eyes or ears. But if a child has extra fingers, the extra ones are simply cut away at birth by any woman who is acting as midwife.

The reference to extra fingers is of interest, for, Rattray (1952) informs us that among the Ashantis of Central Ghana an infant born with six fingers was killed at birth. While minor birth defects such as club foot are tolerated by the Igede, severe malformations are not. Idikwu states, "Abnormal babies are usually killed and thrown away by the Ebih priest" (1976:34). Following the delivery of a malformed baby both parents have to undergo elaborate purification rites, including shaving and bathing by the Ebih priest. Ilogu (1974:24) states that in the past among the Igbo and some other groups infanticide sometimes occurred following the birth of twins. These groups associated multiple births with animal reproduction and the birth of twins was considered unnatural. In such cases the infants were often "thrown away" i.e. abandoned in the bush rather than being put to death by a human agency. An explanation for this is provided by Danquah (1977) who states that among the Ashanti of Ghana, severely retarded infants were abandoned on river banks or near the sea so that such "animal like children" could return to what was believed to be their own kind. These ideas may be abhorrent to modern

sensibilities, nevertheless, Mallory (1992) argues persuasively that "passive euthanasia" can be seen as "contextually rational behavior" when one considers that the community in question possessed neither the time nor the resources to care for infants with extreme physical needs. It is necessary to emphasize that we are discussing the past and attitudes have changed. Although among the Igede beliefs in Ebih persist, most of the population prefer to receive medical treatment or deliver babies at hospitals or health centers where more enlightened responses prevail. It is pertinent to point out that Ebih is thought to be self-generating; the occasional but unavoidable incursion of chaos upon the natural order of things. Although, on occasions, Ebih can be induced unwittingly by human behavior it is not considered a form of divine retribution or ancestral punishment for sins committed, nor is it attributed to witchcraft.

Apuruja

Among the Igede, certain mental illnesses are thought be caused by *Apuruja*, a supernatural force that is believed to make someone mad if it enters their head. As related to me by Igede informants, someone afflicted by *Apuruja* will sing, dance, talk out loud, and cry for no apparent reason, and are even thought to talk in tongues and prophesy. The affected individual has extra energy and may perform unusual acts of endurance such as hoeing a field in the night without stopping. The healing rituals involve singing and dancing while the afflicted person is decorated with certain leaves thought to possess curative properties. It is noteworthy that, on being cured, the individual will become a member of the *Apuruja* cult and thereafter will participate in the cure of other *Apuruja* patients. Thus it can be observed that both the cure and subsequent behavior of a person affected by this mental condition have religious overtones and a practical orientation.

In order to combat the misunderstandings and dearth of information that exist, more research is needed on traditional African attitudes towards disability.

Ancestral Retribution

Generally in Africa, the ancestors are thought to be omnipresent, but invisible, watching over human society and influencing their lives (Nicholls 1984). When the symptoms of an unhealthy society manifest themselves this is thought to offend the ancestors and the high moral standards they represent. Writing of the Ibibio of Nigeria, Offiong (1984:79) says that the relationship

of African ancestors to living kinsmen can be both punitive and benevolent. In their punitive aspect, "disobedience to ancestors causes infertility, the death of children, the birth of only female children, sickness, accidents, and many other misfortunes." Here indeed are elements of divine retribution and Anyaaunwa (1977) of the Ngwa Igbo ethnic group reports that he was told as a child that a neighbor was deaf because he had not given his father an appropriate funeral. Against this, Ilogu (1974:36) emphasizes the benevolent aspects of the Igbo ancestors who, "work conjointly with Ala (the goddess of the earth) in protecting the community from harm in the form of famine or epidemics."

Ndembu Healing Rituals

Anthropologist Victor Turner's book *The Drums of Affliction* (1968) examines the healing rituals of the Ndembu of Zambia. His analysis of the attribution of the cause of particular kinds of mental disturbance among the Ndembu and its treatment is revealing. It shows how the punitive attentions of a troubled ancestor can be neutralized and turned to good. When an individual suffers from insomnia, recurring nightmares, depression, has a nervous breakdown, or whose life is otherwise out of joint, he or she is diagnosed as having entered a disunified position within the cosmological order of things. The cause is often attributed to a neglected or forgotten ancestor who requires attention and has chosen that person to become his devotee. The cure requires that the patient sit on the ground in an attitude of humility while songs, dances, and rituals that portray the cosmological order are performed around him or her. On being cured, the former patient will make regular devotions to the ancestor and may set up an alter or start a cult dedicated to that ancestor. As with *Apuruja*, the remedy for personal crisis is conceived to be religious behavior in which the former patient becomes an advocate for the entity which created the disturbance. A striking example of turning a negative into a positive. The ancestor is not seen as punishing the individual so much as awakening the need for filial responsibility and an exploration of the subconscious dimension of human life.

The conceptualizations of the Ndembu can be compared to the ideas of psychologist Carl Gustav Jung whose sojourn in East Africa no doubt influenced the development of his ideas. Jung's notion of the "collective unconscious" equates in some ways to the ancestral beliefs of Africans. For Jung (1964:107) the collective unconscious is "the part of the psyche that retains and transmits the psychological inheritance of mankind." At the seat of one's personality in the unconscious mind, the collective unconscious (ancestors) impinges on the individual's consciousness and can affect one's moods, attitudes, and behavior. Sigmund Freud's notion of an "archaic heritage"—symbolic archetypes inherited from the human psychic history—

coincides with these ideas. In his book, *The Voice of the Earth* (1992), Theodore Roszak outlines his ideas regarding a human-centered universe. He conceptualizes the existence of a "Mind at Large" that closely resembles what most people call God. He proposes that deep inside each individual is a connectedness with the earth (albeit repressed) that is similar to Jung's collective unconscious, but physical as well as mental. For Roszak it is "the repository of an evolutionary record that ties the psyche to the full sweep of cosmic history." By means of this subterranean faculty we can hear the voice of the earth or, in African terms, the ancestors.

As a psychoanalyst, Jung saw dream imagery as extremely significant. He believed that some of the symbols that appear in dreams are derived from the collective unconscious. He states:

> These symbols are so ancient and unfamiliar to modern man that he cannot directly understand or assimilate them. It is here that the analyst can help. Possibly the patient must be freed from the encumbrance of symbols that have grown stale and inappropriate. Or possibly he must be assisted to discover the abiding value of an old symbol that, far from being dead, is seeking to be reborn in modern form (1964:107).

This description correlates almost exactly to the Ndembu diagnosis and treatment of the individual disturbed by a neglected ancestor who, in Jung's words, "far from being dead, is seeking to be reborn in modern form." Art philosopher Herbert Read (1970:196) maintains that in modern Western society, "the individual has cut himself off from the collective unconscious.... He has only been able to achieve this separateness by repressing his instinctive life and this repression is responsible for his mental disease—his psychoses and neuroses."

Obatala

Certain beliefs of the Yoruba of Nigeria support the notion that people with disabilities are special people in that they have a special relationship with particular deities or spiritual entities. The Yoruba are a large, widely dispersed ethnic group, and regional variations of the pantheon are apparent. Most Yoruba groups share the belief in a "sculptor divinity" who shapes the form of human beings according to his own dictates. Adeoke (1977:6) attributes *Orisannla* as being the Yoruba sculptor divinity. He states:

> Orisannla was believed to be the sculptor divinity. He has been given the prerogative to create man as he chooses. He makes men of shapely or deformed features. Hunchback, albinism and crippling conditions are regarded to be special marks of his prerogative either signifying his displeasure at the

breach of some taboo or to show that he could act as he likes.

For art historian Ulli Beier (1969) who studied the Yoruba of Ede town, *Obatala*, is the sculptor deity and as such holds a unique place in the Yoruba pantheon. For *Obatala*, people with disabilities are particularly precious. Although in the Ede myth of creation, the gift of life is the gift of *Olorun*, the Supreme God, *Obatala* is credited as the artist god who creates the form of living things. As Beier (1969:12) explains:

> The creation story of the Yorubas says that Obatala created human beings out of clay. When he had finished molding their forms he would give them to Olorun, who would blow the breath of life into them. One day, however, Obatala went drinking. That day he created albinos, cripples and blind people. In memory of that day, the worshippers of the Orisa (deity) are forbidden to drink palm wine; and afflicted people are considered to be especially sacred to the god and they are given positions of some importance in his shrines. Obatala is still held to shape the embryo in the womb of every pregnant woman.

The idea that mankind was created by a god out of clay is very widespread indeed. Frazer, in his Folklore and the Bible, gives creation myths from the South Seas, Eastern Asia, Australia, and from the Arctic Regions; and everywhere there is the same idea of man having been created out of clay. But the occasion when *Obatala* got drunk and created abnormal people appears to be a facet unique to Yoruba belief. It also throws a touching sidelight on their mind, the god being very much a human god. Even *Obatala*, the purest of all the deities, is allowed his little weaknesses—but the cripple, the albino and the blind man are given reassurances. Not only are they the creations of the same god but they are his own special favorites, with a special place in his form of worship which no one else can fill. This myth is significant and typical of the strongly developed social sense and the large measure of kindness and tolerance which are the prime virtues of *Obatala* worshippers.

Abiku

Another example of the special regard that Yoruba deities have for persons with impairments concerns *Abiku* children. To understand the Yoruba concept of *Abiku*, it is important to realize that the Yoruba believe that if parents have children that repeatedly die in infancy, it is considered to be a single child that is striving to be reborn. The *Abiku* child is one that is thought, for one reason or another, to have little chance of prolonged survival. Beier (1969) outlines the characteristics of children identified as *Abiku* children:

> The Abiku child is recognised soon after birth. There are well-known signs—usually fits and cramps. Epileptics are usually considered to be Abiku (p. 63). The Abiku is often a 'problem child.' Many of those I have known combine terrible lust for life with depressions and suicidal tendencies. They are very temperamental and make great demands on the parents.... The Abiku is nearly always the unusual one, the out of the ordinary child. In many cases it is the exceptionally brilliant child (p. 64).

A Yoruba mother is quite willing to care for her spirit child, but *Abiku* die young and she knows her chances of keeping it are small. She will devote her every effort to persuading the child to stay with her. Thus, *Abiku* are given exceptional treatment. But this does not offend the other children, who are treated much more sternly, because they know that *Abiku* are special children. Due to this affinity with death an *Abiku* child is considered to be a "spirit child" and while young are believed to entertain invisible playmates (*Egbe*) from the spirit world. *Abiku* children have special responsibilities to their spirit companions, and, according to Beier, "A shrine may be set aside in the forest, where offerings such as kola nuts, yam and even goats may be left" (pp. 63-64). He states:

> Most Abiku have frequent visions of their companions. Some will associate their visions with water or with trees; and nearly all will have them only when alone. Many literate adults who were Abiku as children, have stated that they used to play wonderful games with their spirit companions, and that they even preferred them to their human playmates. On the other hand the spirits will frequently tempt a child to throw itself into water or do other things that may result in its death (p. 64).

Abiku children form special music and dance associations named *Egbe* after their spirit companions. During certain festivals they cover themselves with cloth costumes and perform special songs and dances for the chiefs. If an *Abiku* child survives into adulthood it is thought that the kindnesses of the parents persuaded him to stay and he becomes an ordinary member of society. Regarding *Abiku* children and the role they occupy in Yoruba society, Beier states, "The Yoruba society has solved the educational problem of how to give the exceptional child the freedom it requires to develop its personality, while at the same time supplying the more rigid discipline which the average child must have to feel secure."

In order to combat the misunderstandings and dearth of information that exist, more research is needed on traditional African attitudes towards disability. The examples provided above show that this complex area cannot simply be reduced to a discussion of witchcraft or punishment from the gods.

Instead it has been demonstrated that academic discussion can be illuminated by the insights gleaned from traditional African modes of thought.

It is clear that African attitudes toward people with physical or mental disabilities is an area worth exploring. There are various ways such research might be conducted. One way might be to choose one society or people (Igbo, Yoruba, Igede, etc.) and show how the main ideas relate to concepts of personal identity, success, roles, and achievement in that society. Another way would be to choose a discipline, a perspective (religion, psychology, anthropology, aesthetics, etc.) and examine one aspect of the lives of persons with disabilities (their recognition, their roles, their acceptance into society, their power, etc.) in a number of different societies. Either of these two research approaches would contribute to the body of knowledge in this area. Possibly one of the most fruitful approaches would be to explore how African societies take care of those born with disabilities and how that relates to concepts of special births in general. This would be a rich area of research that could serve to dispel some of the unfortunate stereotypes about African societies that are so prevalent in the West.

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CHAPTER THREE
Development and Disability: Voices from the Periphery - Zimbabwe

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James Charlton has been employed in a leadership position at Access Living for the last six years. The positions he has held include the Director of Programs and Executive Vice President. In both he has had administrative responsibility for most of Access Living's staff positions.

In addition, for the last eleven years he has been deeply involved in the disability rights movement both locally and nationally. He has been most interested in issues as they relate to the continued segregation of the disabled community and how and why disability related organizations have emerged to confront discrimination.

Having travelled throughout Central and South America and, through an IEEIR fellowship, to Zimbabwe, Charlton has been able to have discussions with many disabled activists on how they perceive barriers.

I want to briefly describe and analyze the major contradictions that the disability rights movement in Zimbabwe confront within the context of underdevelopment and dependency; that is, how the ironies and complexities of the economic, cultural and political milieu of Zimbabwe today influence the lives of people with disabilities and their movement for equality and rights. From this, I hope the reader will gain a better appreciation of how people with disabilities, given specific circumstances and histories, have developed modes and patterns of organization that contribute to the overall progress of their communities.

My approach is to use edited interviews of four leading disability rights activists in Zimbabwe to help describe through narratives their experiences and analysis. These interviews were conducted in March of 1992 on a study-visit supported by the University of New Hampshire's International Exchange

of Experts in Rehabilitation. I do this because I am not an expert in any of the broad areas covered by this paper and also because I believe that much can be learned from the exchange of stories, information, strategies and experiences across and between cultures regarding community based movements struggling for social change.

...to understand anything about disability as a social strata or the disability rights movement (or any other movement or social strata for that matter), one must have some understanding of the political economy that group or movement is operating within...

Many people with disabilities have long sought out the common experiences of each other to enhance their own ability to contribute to the successful organization and development of the community. This is especially true in places and countries in great flux where social change is happening on a grand scale, and where empowerment and innovative strategies are necessary to survive.

There are two major observations I want to make at the outset that provides a framework to read this paper. First, to understand anything about disability as a social strata or the disability rights movement (or any other movement or social strata for that matter), one must have some understanding of the political economy that group or movement is operating within; that is, what are the political, social/cultural and economic barriers to social progress. Secondly, the disability rights movement is an anti-systemic movement that is confronting the realpolitik of Zimbabwe. In some ways it is possibly the most influential and organized of these movements in Zimbabwe today. In this regard, I believe that the disability rights movement is one of many movements where new attitudes and worldviews are being created through their struggle and vision that require fundamental structural changes in everyday life.

Development and Disability

"The old is dying and the new cannot be born; in the interregnum there arises a great diversity of morbid symptoms." (Gordimer, p. 1)

At the beginning of Nadine Gordimer's novel *July's People*, the author reaches back to take Antonio Gramsci's famous dictum about the dislocations of development to set the stage for a story about the irony of how a white South

African family survives in a rural village during the final stage of revolution in that country.

Early into my trip to Zimbabwe I had two experiences reflective of Gordimer's irony. The first was a short conversation I had with a street vendor in Bulawayo who wanted to make a deal so he could get a bus ticket to South Africa. How incredible I thought ... here was a man in his early twenties who wanted to go to Johannesburg! When he said Johannesburg I asked if he was serious. He took a moment, smiled and said, "Well, I probably will have to stay in Soweto". Another example came in the course of a series of lengthy interviews I did with disability rights activists, members of the National Council of Disabled Persons of Zimbabwe (NCDPZ). When the subject of African culture and attitudes was discussed, the three people most associated with the development of the NCDPZ, attributed great significance to their association with various white "Rhodesian" (their term) educators who had encouraged them at one point or another. In contrast, each spoke of the isolation and disrespect they and their families were subjected to by people in their own village because of their disability.

When one travels to Zimbabwe today it is not possible to avoid the ironies, contradictions and complexities of everyday life in a country really at a place inhabited by three social systems or formations. At an interregnum indeed!

The primary social formation is a feudal, rural society and culture characterized by subsistence farming, plantations, isolation, and superstition. Less important is a capitalist urban "sector" that exists in Harare and Bulawayo (the only two cities with significant populations) where a limited but still extensive private market operates where quality goods and services are available. Finally, a socialist and nationalist governing party tried a short-lived attempt to create a socialist state resulting in a nascent, almost irrelevant socialist project which probably should not be categorized as a contending system but I add it anyway out of respect. These structural characteristics of course are not so different from many countries in the so-called "Third World". They must nevertheless be recognized each time one analyzes the possibilities of social, economic and political progress.

Briefly, Zimbabwe is a country of contrasts between rich (mainly the 200,000 remaining whites) and poor; the urban and rural; black and white; large plantations and subsistence farming; the healthy and sick and so on. Moreover, Zimbabwe is facing a confluence of forces that is creating a profound social crisis. These factors include the worst drought in the country's history, the continuance of apartheid in South Africa, extraordinary rates of HIV infection, and an economic austerity program imposed by the IMF and World Bank.

In addition, Zimbabwe's governing party, the Zimbabwe African National Union (ZANU PF) is increasingly attacked by former supporters for the slow pace of economic/agricultural reform and the corruption of some party officials. In Zimbabwe we are witnessing two contradictory developments. On the one hand, growing social dislocation and decay, disillusionment, and impatience, especially on the part of the masses of people who were mobilized around national liberation and at the same time new forms of self reliance, popular resistance and organization.

Disability Rights as a Political Movement

"Consequently, 'antisystemic' forces and movements are those that call into question this inequality, refuse to submit to its consequences." (Amin, p. 100)

Samir Amin further noted that the phenomenon of new popular and "antisystemic" movements was bound up with the dual crisis of economics and political struggle when he wrote, "For the expansion of capitalism in the periphery precisely ruins the chances of national crystallization, and accentuates the fragmentation and atomization of society. The crisis of social movements, the emergence of new forms of social grouping around basic communities (family, regional or ethnic, religious or linguistic) and the cultural crisis of our societies testify to the effects of capitalist peripheralization." (Amin, p. 124).

To Amin's list of new forms of social and community groupings, I would add people with disabilities and the disability rights movements.

I believe that the disability rights movement is one of many movements where new attitudes and worldviews are being created through their struggle and vision that require fundamental structural changes in everyday life.

Organizations of disabled people are emerging in Latin America and Africa and becoming viable social movements. We have much to learn about how and why these groups were formed and what sustains them. The importance of these groups will only grow over time. According to a Government Accounting Office report of February, 1991, the United Nations estimates 80% of the world's 500 million persons with disabilities live in the developing countries.

Not only are there more disabled people in the third world, but the percentage is growing. Writing in *Rehabilitation International* (1981), in an article "Population and Development Problems Relating to Disability Prevention and Rehabilitation," John H. Nobel, Jr. states that: "In 1975 people throughout the world suffering all types and degrees of disability numbered an estimated 490 million (12.3 percent of the world population); by the year 2000, their number will reach an estimated 846 million (13.0 percent). Whereas in 1975 more than three-quarters of this population lived in developing countries, by the year 2000 more than four-fifths of all disabled people will live in these countries".

I went to Zimbabwe because I was interested in the reasons for the growth and development of disability related organizations there specifically and in southern Africa in general: how, in fact, these groups were flourishing in spite of the barriers of underdevelopment. Indeed, Zimbabwe is a good example because it is in many ways the most developed country in Africa (outside white South Africa and Arab northern Africa) which allows one to make the assumption that whatever development barriers exist in Zimbabwe exist elsewhere and may be of greater magnitude. Most importantly, I wanted to identify the political and organizational features of Southern Africa Federation of the Disabled and the National Council of Disabled Persons of Zimbabwe.

Observations on SAFOD and NCDPZ

The Southern Africa Federation of the Disabled (SAFOD) was formed in 1986 as a federation of non-governmental organizations of disabled persons in the Southern Africa Development Coordinating Conference countries, and accepted representatives of anti-apartheid disabled persons in South Africa. The aims of SAFOD are to provide means of enabling representatives of the 7.9 million disabled people in the region to meet each other and to benefit from one another's experiences. Specifically, they are to support the formation of disability related organizations, the training of disabled people to be leaders of these groups and to facilitate exchange of information in the field of disability through public education programs, seminars, travel and exchange, conferences, and publications concerning all aspects of the lives of disabled people

SAFOD has a secretariat in Bulawayo, Zimbabwe, with a small staff headed by a Secretary General. SAFOD is a sub-regional member organization of Disabled Peoples International (DPI) and has links with other international organizations of disabled. Countries eligible to have member organizations are:

- Angola
- Botswana
- Lesotho
- Malawi
- Mozambique
- Namibia
- South Africa
- Zambia
- Zimbabwe
- Swaziland

SAFOD is governed by an Executive Committee, elected at each bi-annual General Assembly and drawn from the national organizations. Office holders on the Executive Committee are elected by the General Assembly, as is the Secretary General, who is the chief administrative officer of the organization.

SAFOD has a Regional Development Plan for Southern Africa which includes the following programs:

- Public Education
- Self-Help
- Accessible Dwelling Environment
- Small-scale Enterprises for Economic Development
  Training and Exchange
- Women's Regional Development

The National Council of Disabled Persons of Zimbabwe (NCDPZ) was registered as a welfare organization in 1975 as the Council for the Welfare of the Disabled. In 1983 the name of the organization was changed to NCDPZ.

NCDPZ is a mass membership organization of disabled persons, as well as some non-disabled friends and relatives who endorse the objectives and are willing to participate in the work of the organization. The objectives focus on promoting full integration into Zimbabwean society of all disabled persons and active participation by the disabled in the planning and decision-making processes that affect their own lives. NCDPZ does this by supporting and providing self-help projects among disabled people. A membership subscription is payable each year, but no disabled person is barred from membership for lack of money.

Members meet together locally on a regular basis as NCDPZ branches and elect their own leaders. They govern themselves. Branches offer support to individual members who share similar problems. The actions of the members have advocated for better conditions in such areas as employment, education, housing, transport and mobility. The work of NCDPZ involves: advocacy, grassroots organizing, training and leadership development advice to member branches on project planning.

Leaders and activists from the branches compete for election to the National Executive Committee of NCDPZ consisting of 15 members. They, in turn, elect their national office holder, set policy at the national level, and appoint an Executive Director as the person responsible for overall manage-

ment of the affairs of the organization. The national office is in Bulawayo with a salaried staff of 18 people with disabilities.

NCDPZ has the following programs in place:

- Appliances
- Leadership Training
- Public Education
- Scholarships
- Women's Programs
- Freedom Supermarket—(self-help demonstration project)
- Membership Development

These groups have been actively and successfully organizing people with disabilities for a number of years. Organizing efforts have been complemented with the *Disability Frontline* newsletter (SAFOD); the SAFOD *Development Activists Handbook* (by Machenzie Mbewe and Peter Lee) leadership and training seminars by SAFOD, NCDPZ, and the Zimbabwe Federation of the Disabled (ZIFOD).

The philosophy of SAFOD and the NCDPZ is consumer control, cross-disability and empowerment. These tenets are fundamental and run through all of these organization's activities and projects.

A major outcome of these efforts was a recent conference (August 24 to September 6, 1991) in Harare where 40 delegates came from all over Africa to discuss disability issues. One of the outstanding achievements of the seminar was the adoption of working guidelines and the "Harare Declaration On the Establishment of the Pan African Federation of Disabled People" which was signed by all the delegates.

It was noteworthy to see the relationship between SAFOD and NCDPZ and between these groups (especially as individual activists) and other organizations like the Zimbabwe Sports Association of the Disabled, the Zimbabwe National League of the Blind and the Zimbabwe Down's Children's Association. These links have been built through the Zimbabwe Federation of the Disabled (a national coalition) and function quite well. This has yielded some important early gains in the area of education in Bulawayo and Harare where conscious efforts have been made at educating children with disabilities in an integrated setting.

Both SAFOD and the NCDPZ have paid staff although NCDPZ is much

larger. They have been funded by northern European (aid/economic development) foundations such as Action on Disability and OXFAM. These foundations support specific programs or purchases like a personal computer or agency vans. All of the key people in SAFOD and NCDPZ emphasized that ongoing funding was a big issue. This is especially true in Harare, where the NCDPZ is trying to secure funding for a shoe factory. While they were given the land in Highfields (a high density township of Harare) they need $50-75,000 (U.S.) to get the project going. This is typical of any major fee generating project. Smaller projects like gardens and grain mills are usually capitalized out of members' labor.

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Both SAFOD an NCDPZ are widely recognized throughout Zimbabwe. In addition, Joshua Malinga, Alexander Phiri and Rwanga Mupindar are nationally recognized. They have access to government leaders, politicians and policy makers including President Mugabe. Malinga is also a city council member and a ranking member of the Zimbabwe African National Union (ZANU), the ruling party. Dean Makamore of the University of Zimbabwe Law School told us the NCDPZ was probably the most organized and visible "interest group" in the country.

Interviews

In the course of three weeks in March, 1992 I interviewed twenty-five disability rights activists. Their stories and experiences speak directly to the need for a movement of people to take on the social institutions, government and prevailing attitudes in the country. The following represent a small sample of 50 hours of interviews. These comments are edited and grouped into some general areas. They included **Joshua Malinga (JM)** - General Secretary of SAFOD and Disabled People's International, **Alexander Phiri (AP)** - Chairperson of NCDPZ, **Rwanga Mupindar (RM)** - Executive Director of NCDPZ, and **Lizzie Mamvura (LM)** - Women's Project Coordinator at NCDPZ. What follows are excerpts of what was transcribed in these four representative interviews:

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Q: I've been interested in disability culture and politics for in many years. Given the growth of disability rights and disability related

organizations, Zimbabwe seemed really important. Specifically, I'm interested in your personal experience and political development. What connection is there between disability rights, African culture and the specific Zimbabwean experience? When and why did all the disability related organizations begin? What kind of influence and impact has SAFOD and NCDPZ had on other groups and other movements?

J.M. I was born in 1944 about 100 kilometers from Bulawayo. As you know, we in Zimbabwe have two homes, one in our village and also in the city where we must go to find work. My father was a village chief and had 6 wives and 38 children. I was the only one to get polio.

Now in Africa we have very backward ideas about disability connected to witchcraft and to life as an oppressed people historically.

From early on, all my brothers and sisters went off to school and I had to stay home to scare away the animals from our house and do errands.

Everything I am now, it's all because of accidents of fortune. In 1956, the first accident of fortune occurred. One of my brothers had an accident, broke his arm and found himself in the hospital. There, my brother met this man, Jauros Jiri who was developing a social service network which now is a very big charity agency of 25 to 30 institutions. My brother talked with Jauros Jiri about his situation and Jauros Jiri said he was trying to help disabled people — he used other words but that is what he was attempting. After this discussion, my brother told Jauros Jiri about me, so Jauros Jiri organized for me to come to the institution. Although my parents didn't want me to go, there was obviously nothing at home for me. I was very young (13) but had never been to school so all this was very new.

Jauros Jiri began to train me in leathercraft and I had some classes for reading and math. Their only idea for me was to be a cobbler.

In 1959, there was another accident of fortune for me. In that year, Jauros Jiri received money from the government to bring in a trained teacher. This teacher noticed that education was easy for me and he encouraged me to go to school. Although, the people at the institution didn't want me to go but because this teacher within the institution was the one encouraging me, it was hard for them to stop me.

Even from day one, I had an inborn attitude not to accept the attitudes at Jauros Jiri. These ideas were very bad e.g. disabled people were told when to eat, when to sleep, that they couldn't make love — it was banned!. Especially in the period 1965-67, I had a growing consciousness about

disability. By the mid 1970's along with a few others, we wanted to reject all these ideas and start our own organization.

By 1965, I began organizing disabled people because I knew things were not right. First, we called ourselves "Inmates Representative Council" and then "Trainees Representatives Council." Later we became Council for the Welfare of the Disabled and then National Council for the Welfare of the Disabled.

In fact, I was the first Jauros Jiri person to go through primary and secondary school. Then I went to technical college and was probably the first black to go to technical college in Bulawayo. When I left college I could not get a job except at Jauros Jiri. My jobs escalated there from accountant to bookkeeper to administrator of the biggest Jauros Jiri project. When I left in 1980 I was the CEO of Jauros Jiri. At that time, another accident of furtune occurred.

1980 was also an important year because at this time Zimbabwe became independent. At this time a fellow from OXFAM visited Jauros Jiri to see about funding their programs. In the meeting I could tell he didn't want to fund a charity. I think he was mostly interested in development not services. So anyway, during the meeting I slipped him a note asking could he meet me after the meeting and he said OK.

So when I met him, I told him that I detected he had some reservations about Jauros Jiri and I told him about a disability group I was involved with, that we were starting to organize but we had no funds. That we had to take paper and other materials where we could and that we needed an office and secretary and some other things. I told him, Oxfam should fund us because we were interested in civil rights and changing the world. He said OK. So this helped greatly. Then I said that I knew about this upcoming international conference in Canada and could he find funds for me to go. This did happen and I went to Winnipeg in 1981 to attend the Rehabilitation International (RI) Conference. As you know, 1981 was the International Year of Disabled Persons, a year dedicated to full participation of disabled persons. But RI didn't really practice this. At this conference there were 5000 delegates but only 200 disabled persons. So, the disabled delegates got together and demanded the executive committee be 50% people with disabilities. That was overwhelmingly rejected so there was a split and the 200 disabled persons and some others formed Disabled People International of which I have held various posts. I am the current Chairperson until 1994.

When I returned from Winnipeg in 1981 I was a changed person. When I left I was very passive, when I returned I was very radical. Immediately, we changed our name from National Council for the Welfare of the Disabled to

NCDPZ. At that time, we began to recognize that disability was about human rights, about social change, about organizing ourselves. We did not want to emphasize welfare but organization.

A.P. I wasn't born disabled. I became disabled at the age of ten from an accident. Because of complications I had my legs were amputated.

I was born in Malawi. After my accident, my parents visited two or three times and then I was abandoned. When I was to leave the hospital, the hospital people tried to locate my parents but failed. It was clear that they did not want a child they considered useless. Families have lots of children in Africa to increase the chances that one of their children will get a good job and provide for them when they are old. My parents thought I would only be a burden. They also did not want to deal with the social implications in their village for having a disabled child, because they would be ostracized and maybe even ridiculed.

Fortunately, there was a white lady nurse who became interested in me. She brought me into her family. She later arranged for me to live in an institution to study and learn a trade. I had a good skill at painting and some of my pictures were even sold at auctions.

This brings me to 1975 when many of us were living in this very large charity association called the Jauros Jiri Association. Well, we didn't like our living circumstances in this place.

I was involved from the beginning but it was probably in 1975 that I became a real activist. This was when I was elected branch chair of the NCPDZ while I was still a student. I must admit I didn't know much but I pushed forward.

We started out as a recreational group but whenever we got together, we only talked about our complaints. For example, we did not have adequate mobility devices. We were told when to eat, when to sleep, even though we were adults. So we eventually organized into the Council for the Welfare of the Disabled. It's interesting that when we got started, the rehabilitation industry tried to destroy us. They told the government that we were part of the guerrilla movement at that time. This could have created very difficult problems for us, the white government could have crushed us. Fortunately, after the government investigated us, they allowed us to become an official organization. From then until 1980, we only were based in a few urban areas and it was very difficult for us to begin.

"After my accident, my parents visited two or three times and then I was abandoned. When I was to leave the hospital, the hospital people tried to locate my parents but failed. It was clear that they did not want a child they considered useless."
...Alexander Phiri

Following liberation in 1980, the government began strongly supporting rural development, so we were able to link up with these efforts to do outreach into the rural areas.

I think when we started it was like a rebellion, and I was always quite rebellious, quite assertive. Remember, we started within this institution, we rebelled against this charity and society at the same time.

During the early eighties there was a lot of development opportunities because there was a lot of international interest in Zimbabwe.

While we had to take advantage of these opportunities, it also had the effect of underdeveloping our organization. This was because the funding agencies had their own ideas about what projects should be started and many of these did not bear fruit. They did not correspond with our reality. The fact is we were young and had never worked with these development agencies before, so we took the money. Unfortunately, these projects were many times a waste of time. Of course, these agencies wanted something tangible, something they could take pictures of so they can raise more money. For example, they wanted us to do poultry projects by keeping chickens to generate income. But what would happen is that the disabled members would become hungry and eat the chickens, which would diminish the projects'sustainability. Another were vegetable gardens that were set up in areas where water was scarce so the projects failed. This was demoralizing as well. So when we analyzed this, we recognized our main efforts had to be disability rights not vegetables or chickens.

Of course, you don't eat politics but by analyzing the failures of the projects of the mid-eighties (after the formation of SAFOD), we emphasized that our projects had to focus on empowerment. So, this is what has happened.

A most important recent result of our efforts has been a draft of a new disability law developed by the ruling party. We rejected the first draft in July 1990. When we did this, we were threatened and the Minister of Social Welfare yelled a lot but we told him very firmly, that any bill designed for us we wanted input on. The most recent draft is a result of an all day meeting we had in

Harare. The only reason we have been given this importance is because we now have a considerable influence on public policy relating to disability.

Oh yes, we are being copied by many others. They are using our terminology — "equalization of opportunities". They are also using our tactics of speaking out — e.g. rehab assistants and recently health workers have been copying us in their struggles with the Ministry of Health. This is happening even though they don't know what it means — they see that we are making changes.

We have been so successful that lots of organizations are trying to work on disability related issues like the UN and UNESCO. This has not always been good because it confuses a lot of people within the movement — that is, how to relate to all these groups.

We have always stressed our independent role, that disabled people must control the issues that directly effect us. Our principles are self representation, emancipation and self determination and independence. All our members must agree with these and our constitution.

There are many groups, but most importantly we don't want to be separated. We must guard against this — you know divide and conquer. So we set up the Zimbabwe Federation of the Disabled (ZIFOD) to have all these groups together. Presently, I am chairman. This is rotated every 4 years. It is given to an organization not individuals. This year NCDPZ is Chair, the Sports Federation of the Disabled is Secretary, the Federation of the Blind is Vice Chair and so on.

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...Alexander Phiri

R.M. A discussion erupted within my family when I approached the time to go to secondary school. My mother said I could stay home and she would look after me. My father said I should go to Jauros Jiri to learn a craft. I said no! I said my sister is in secondary school and I have done better than her in both my grades and entrance exam. I was very persistent. I said

everyone I knew who went to work for Jauros Jiri ended up destitute on the street. So a compromise was reached whereby I would stay at the institution and go to secondary school.

By then we began analyzing the problems of this institution. We were listening to the liberation radio programs at night from Mozambique and this was very influential on us. The institution banned these radio broadcasts but we listened anyway.

We began to organize strikes and demonstrations. We started our organization within the institution, it really scared the institution's authorities. We also set up a scam, to pay for our organizing efforts. You know, many people gave donations to Jauros Jiri but they were never passed on to us so we called together this group of criminals who were living close to the institution and we told them that we would get these donations to them so they could sell them on the black market if we got half. They thought we were cool to call on them so we made a deal. This scam lasted two years. It was a lucrative deal for us and helped us get paper, supplies, etc. When we were discovered, I was dismissed. Jauros Jiri said they had nothing else to offer me. So I went home. That was in 1978. I had learned a lot about organizing during this time.

That year, the rural area where I lived was a liberated area and when the so-called security forces came, I came out and convinced them that my parents could not be working for the guerrillas because they were taking care of me. They believed me. Also, I wrote a letter to the guerrilla leader in this area, asking him not to recruit my mother because she was needed at home. They agreed and my family really appreciated this; that I had saved them from the ongoing warfare. This is another irony of my life I guess, where my family benefitted from the negative attitudes people had about me.

During my school years, we had many projects going to raise money like secretly bringing in beer to sell to the other students. Remember, this was a missionary school. One night the Head Master appeared when we were drinking and smoking. Everyone ran away and ducked out the windows but I could not get away. So the Head Master demanded I give him the names of all the other students who were drinking. But I told him I couldn't because I had to rely on these guys to assist me at times.

Of course, Jauros Jiri wrote a letter threatening to withdraw my scholarship but ended up taking my transportation away. So I had to get pushed (in my wheelchair) four kilometers each day to school. To get pushed, I gave up my dinner meat dish to the person who pushed me. Also, I had to resort to providing school tutoring to various people. Finally, I became good friends with a guy who lived close to the institution who pushed me for two years.

After this I became active in NCDPZ, becoming Bulawayo branch chair. Also I got close to Phiri and Malinga who became my mentors. They began to incorporate me into the high-powered discussions they were carrying out.

Fortunately, I ended up with a job at the railroad and I held this position until 1989 when I became Executive Director of NCDPZ.

"We began to organize strikes and demonstrations. We started our organization within the institution, it really scared the institution's authorities. We also set up a scam, to pay for our organizing efforts. You know, many people gave donations to Jauros Jiri but they were never passed on to us so we called together this group of criminals who were living close to the institution and we told them that we would get these donations to them so they could sell them on the black market if we got half."
...Rwanga Mupindar

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Q: How do attitudes and myths about disability get expressed? I'm interested in how the political and cultural aspects of everyday life are connected. Have you seen changes in attitudes over time? What are the prevailing attitudes today toward disability? Are there differences between rural and urban areas? Does this reveal anything about the obstacles people with disabilities have in developing a consciousness about their rights and struggle for equality and respect?

A.P. Well, I was very shy when I was young but as I became older I discovered that if I didn't become more assertive, showing my anger, I would always be oppressed.

For example, when I first fell in love I couldn't tell this girl what I wanted. Actually, we both went around and around. We were unprepared for this aspect of life because we had both been told that because we were disabled we would never have a lover.

This is very important because the link between sexuality and disability is so central to our own image of ourselves and the stereotypes about disability. That is, people with disabilities are not able to have sexual experiences, that we are passive, not fully human, always children.

In fact, even today, there is a prevalent attitude that a disabled person can't be a good lover.

I called a press conference and hit out at these companies which denied me a job after they met me. This became a front page story in the newspapers. After this, I was offered three jobs and hence I started my working life.
...Alexander Phiri

I think the attitudes in the rural areas are the worst. These areas have very entrenched ideas, that are very bad, that lead to treating disabled people always like children or worse. We are connected to evil because of rural peoples' notions of witchcraft.

I think there has been a slight change about disability over the years. Disabled people are becoming aware — and through the disability rights movement we have been speaking out, setting examples for others.

Kids are a bit more assertive today because of this work. I met recently with disabled teenagers and I was amazed how the kids just spoke up. Back then we were supposed to be quiet and let someone else do it for us, as it were.

Following school, there were nine graduates who passed the final examination. I was the only one who did not get a job! I would write to all sorts of companies but when they found out about my disability they would just say no. These (white) employers were much more bothered by my disability than my color.

Yes, these are the ironies of my life. I will tell you how I got a job and this was probably a turning point in my commitment to disability rights.

I called a press conference and hit out at these companies which denied me a job after they met me. This became a front page story in the newspapers. After this, I was offered three jobs and hence I started my working life.

In our culture, disability is looked at as shameful not just for the disabled person but for their family. This is connected to witchcraft, to some notions that somehow the ancestors are upset because the family is not acting in the traditional way or honoring them enough. The traditional religious churches do not even attempt to change these ideas because they are afraid of losing

members.

J.M. We began to target attitudes in 1981 because attitudes were key. To this end, we knew that we had to mobilize and organize people with disabilities. You may know that we are beginning to be listened to by the government. In fact, there is an important piece of legislation in Parliament that promotes the rights of disabled persons. But we must be clear that without a movement and organization, this law will not be used. I have heard in India they have a lot of laws for disabled people but they are disregarded because disabled people are not organized, do not demand their rights. We have a similar situation with women in Zimbabwe. I think Zimbabwe has the best laws protecting women's rights in Africa but they are still oppressed because they are not well organized. Negative attitudes brought about charities not movements and when you talk about changing attitudes you don't limit yourself to legislation, it can be an instrument but only that.

"In Africa, in our culture, we do not even use the awful term 'cripple', it's even worse. In Shona, the word is 'chirema' which means totally useless, a failure."
...Rwanga Mupindar

To be disabled in Zimbabwe, people think you are not a full human being. Our activities are not considered normal, you aren't expected to play an adult role. We have a long way to go.

R.M. I think to basically analyze these questions I would go back to my youth. I contracted polio when I was two. People who were superstitious believed evil spirits had cursed me.

In Africa, in our culture, we do not even use the awful term "cripple," it's even worse. In Shona, the word is "chirema" which means totally useless, a failure. So a person with a disability begins their life as a "chirema." This automatically creates the stereotype immediately. This is not the case among whites, by the way. They didn't pity me, they may have regarded me as inferior because I was black, but I didn't get pity.

Periodically, relatives would come to my family's house and they were to ask how are you, how are you managing but they would use a vernacular that really felt like I had just got out of intensive care, like I was dying, like I was sick!

L.M. I have lived in Zimbabwe, Zambia and the U.K.

I suppose my experiences in Zimbabwe have been the worst. In the U.K. people really keep to themselves; they are private so they mind their own business. In Zambia I was young and impressionable but I was spending a lot of time by myself, studying. In Zimbabwe, the attitudes are very backward. For example, in my village, but also in Bulawayo, I was told many times that no man would want me as a woman because I had a disability. In fact, there was a strange man who always said I was his wife and this was very annoying. Finally, after a lot of effort, I built up my nerve and told him to stop this practice. He said no one would want me so he was doing me a favor. I stood up to him and from then on I felt a lot stronger. I felt the power of talking for myself.

The women's project I coordinate has this issue as a major goal. That is, to hold meetings and workshops that train leaders and others to be assertive. To speak up, to articulate our/their rights — the right to work, to get married, have kids. Unfortunately, we are a small minority.

Q: What is the major problem that women with disabilities face in Zimbabwe?

L.M. The biggest is that it's very difficult for disabled women to get married and to find a job. Even if a man is interested in marriage, his parents wouldn't allow it — they believe that having their son marry a disabled woman would bring misfortune or bad luck to the family. Also, employment is difficult because there is widespread unemployment and because Zimbabwean culture expects women to stay in their village and it is doubly bad for a disabled woman because they are shut off by people in the village and even her family.

But I know we must keep on. I encourage women to be supportive of each other.

Q. What was it like during your school years? How did friends and peers respond to your educational goals? What happened when you finished school with a degree? Did your peers at the institution think you were crazy for going to school?

A.P. Oh yes, they were busy making things for Jauros Jiri and making just enough to buy cigarettes. When I would borrow cigarettes from them they would say — why are you wasting time at school when could be working here. They just didn't understand.

My school years were very hard. There was a rumor around school that if you touched my wheelchair you would become paralyzed. So it was initially very hard to get other students to help me. I was a stubborn student. It was really difficult because the school wasn't accessible, the cafeteria, the laboratory, etc. I'll tell you the trick I would use. During holidays I would stock up on cigarettes, so that I could offer cigarettes to the other students if they would assist me with the inaccessibility.

Of course, over time I became a bother. I didn't want to report the access problems because I feared that I would be sent away from school, so I had to always ask others for assistance. I had no control over my life but I had some ideas of what I wanted to accomplish. Of course, I learned many important lessons from these experiences. I learned you must speak for yourself because people will keep you down unless you demand your rights. I had to step on a few toes with my wheelchair.

I wanted to learn drafting. The Technical College was really inaccessible. The officials at the school told me I couldn't make it because of the steps. So I told them a lie — you know sometimes you must do this to survive — I told them I had a friend to lift me — which wasn't true, but they believed me so they accepted me. I was one of only three black students. My trick at this school was to ask the lecturer to give directives to schoolmates to lift me up and down the stairs for the following day. Usually this worked out ok. Sometimes, I had to offer money or help with homework to get help.

R.M. When I was to go into school, when I was assessed, my parents were told that I should be institutionalized but fortunately the head master of the school encouraged me to be integrated into regular school. Many people thought this was crazy but my father who was also a school head master in a rural area said OK we will try it. Of course, everyone opposed this. My family was asked, how would I be punished? How would I use the toilet? How were they supposed to change the curriculum and even could I sing during extracurricular sessions in Grade 1? They didn't even think I could sing!

When I finally got into this primary school, the kids would scream when I would go into their classroom, they would say, I can't go to school with this person who doesn't walk and so on. I became a big bother because the school was so inaccessible and I was the first student ever who used a wheelchair so I was constantly asking for help. As time went on, teachers began to be impressed by me because learning was easy for me. So after the first few years things became easier for me. Finally I passed through primary school.

After the liberation war in 1979, my mother decided to take me back to the very first institution where I created all these problems. How absurd I thought, but I did not know what else to do so when I went there, they said

go to their institution in Bulawayo to do basket weaving. I did this because, during the year I was staying at home, I had lost hope.

"Our task is not only to educate disabled people but other people especially in the short term those who work in the disability field like therapists and social workers. In fact, these people play the role of social control, so we must transform them into our supporters."
...Joshua Malinga

Later, I saw this queue for students to sign up for classes. I just got in line with my test results that I had previously stolen from the administration's office. They had refused to give me my scores. Can you believe this? So my scores were very high. Well, after much to do I got signed up. I was in school beginning in 1980 and I was living at this institution. I was supported during this time by Joshua Malinga who was an accountant at Jauros Jiri. Alexander Phiri also helped me during this time. At the time, Alexander was seen by all of us as a role model, as a clever fellow, who was very articulate and strong. So I perserved.

Q. What role do you think social service agencies and institutions play in the life of people with disabilities in Zimbabwe?

J.M. Charities play a negative social role. They seek to control us. They don't train us for modern jobs like managers, accountants, teachers.

Charities are not interested in empowerment and integration, they support segregation. In fact, once we have integration and equalization of opportunity, these charities will begin to die. Their institutional interests lie with segregation, ours with integration. That is our future, what we must accomplish. Unfortunately, we have to fight with the politicians, the charities and social workers, business interests and others to achieve this.

Our task is not only to educate disabled people but other people especially in the short term those who work in the disability field like therapists and social workers. In fact, these people play the role of social control, so we must transform them into our supporters.

A.P. At age 15 when I passed through primary school and passed the placement tests I wanted to go to secondary school but the institution where I lived said I couldn't go. There were two of us, that had done well and

had applied to a mission school (secondary). The institution said I should forget school and become a cobbler. They had these ideas about disabled people only being able to get by with craftwork. But I proceeded on to apply and was invited for an interview.

When I arrived at the Mission School with a friend, we were asked who would pay the school fees. We told them Jauros Jiri, the institution, would pay the school fees although we did not know this to be true. Later the Jauros Jiri person told me I couldn't go. I cried. They also said they wouldn't pay because it was a waste of money. But I didn't listen and I went anyway.

It was a tough beginning. I didn't get any encouragement from Jauros Jiri or even my friends in the institution.

During all these years, no matter how successful I was in school I was always discouraged. The Jauros Jiri institution offered me a secretarial job and when I refused, people there told me this was the only job I would ever be offered. This is the role of charities to help us by controlling us, not liberating us from all that holds us down.

We are seeing some small changes here as well. For example, two weeks ago I was in Harare, where there is an institution and group called the Association of the Welfare for the Handicapped and we joined these people to meet with the Ministry of Health. The Vice Chair of this group was asked how much money they needed to develop institutions and he said they were more interested in community based programs not more institutions. This of course, was an important development and frankly we were pleasantly surprised. Not surprising though, the Minister began arguing with this representative from the institution. It was quite interesting, funny actually. So that shows that we have had an impact.

"The Jauros Jiri institution offered me a secretarial job and when I refused, people there told me this was the only job I would ever be offered. This is the role of charities to help us by controlling us, not liberating us from all that holds us down."
...Alexander Phiri

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Q: Can you talk about what's going on in the region? Where is the disability rights strongest? Do you think disabled people fare better with a government that is focused on supporting the private sector or

one that has a social welfare orientation?

J.M. When I came back from Winnipeg I was assigned to organize the region of Africa. We Zimbabweans have impacted the organizations of disabled people throughout southern Africa.

I believe in South Africa they have as strong a movement as we have in Zimbabwe, probably because of the struggle against apartheid the disabled community is more politicized, so it has progressed well.

"The reason we stress the separate role of our organizations is that we must advocate for ourselves, always. We should not rely on political parties to liberate ourselves...I will say that we in Zimbabwe benefitted from Soviet aid. Without the AK-47 we might still not be liberated. But all governments, whether socialist or capitalist have separated us from the rest of society."
...Joshua Malinga

The newest is in Angola. It was the hardest to organize because of the destabilization there by South Africa and the American government.

Of course, ninety percent of our problems in the region are directly related to the role of the U.S.

In Mozambique, an organization was formed three years ago which is very well organized although, it was difficult to do, similar to Angola. I think the ruling party (FRELIMO) played a role. We always emphasize the independent role of disabled organizations and our movement from the government. This is the problem we are presently experiencing in Namibia as in Mozambique where most of the disabled people we are working with are excombatants who are very close to or in the ruling party. So our task is to break that relationship up. We do this because we must be independent so we can criticize anyone, even the government. The reason we stress the separate role of our organizations is that we must advocate for ourselves, always. We should not rely on political parties to liberate ourselves. Our progress in all the countries is uneven. We have many barriers but the most important is the level of development in the region.

We have no proof about social systems. All governments treat disabled people badly. They all see us as a burden. In the Soviet Union, disabled people

were not allowed to organize separately. They were totally responsible to the ruling party. This turned out very badly for us there. Now I have heard disabled people became very well organized in Nicaragua after the revolution. So the results are very mixed under socialism.

I will say that we in Zimbabwe benefitted from Soviet aid. Without the AK-47 we might still not be liberated. But all governments, whether socialist or capitalist have separated us from the rest of society.

People are judged ultimately by their own activity. Until we are businessmen, politicians, community leaders, people at all levels of society, we will be marginalized and segregated.

R.M. Whether you are talking about the Rhodesian government or the present government, there is not much difference in how each government has developed public policy concerning us. We have no access to new housing, no access to education and so on. The government has many programs but none of them take us into account.

A.P. Of course, we all were influenced by the liberation struggle that had a socialist aim. We all developed a liking and respect for those guys, the guerrillas and all the whites became in our minds the oppressor. You could never trust them. In fact, during this time I couldn't complain about access problems because I feared they would take me to the police for being an agitator or a sympathizer with the guerrillas. Only a few liberal whites would talk to me. Ironically, it's quite surprising that they would sometimes even encourage me. Whereas black people, while they were much more friendly as a whole would never do this. In fact, while there were only three blacks out of 37 students at technical college, the white teachers were more encouraging to me than the black people I knew from Jauros Jiri. This is another big irony for us.

Summary/Future Challenges, Barriers and a Paradox

"A horde of martyrs burst upon the present,
they march beside the living." (Soyinka)

The struggle against colonialism and imperialism has taken many forms in the last 40 years, some more successful than others. All have been purportedly liberatory. Today, many activists question their relevance. As revolutionary movements have experienced setbacks or worse, sellouts, new social movements have emerged. We used to call the need for this phenomenom, "the revolution within the revolution." I would argue it has been the inability of the failed or even "victorious" revolution to be truly liberatory that

these new forces have developed. They are as much a response to the inability of the revolutionary movement to obliterate oppression as to imperialism itself. The new social movements have a collective wisdom of the past but firmly rooted in people's own personal experiences and needs. I believe these activists have much in common with Soyinka's march of the living. That is, a commitment to social change, regardless of risk.

The disability rights movement in southern Africa is a new social movement that has made limited but remarkable achievements in the last ten years, although we should not judge the "accomplishments" in our own (western) context. The reality in Africa precludes this.

The challenges for the disability rights movement are immense. I want to summarize the four major challenges/barriers I believe will confront this movement throughout the next decade.

The overarching barrier is that for people with disabilities to advance socially there must be an overall development of the economy; Zimbabwe, like all of the "Third World," is an economy mired in backwardness.

Of course, much has been written about these pre-capitalist social and economic formations. There has even been a lot of debate about how to label them. From "archaic" [Polanyi] "tributary" [Amin], "primitive, feudal" [Marx], "pre-capitalist" [Dobb, Hobsbawm], "traditional" [Coquery-Vidrovitch] and so on.

The basic point is that nation states and regions are located either in the "center" (U.S., Europe, Japan) or the "periphery" (everywhere else) and that the capitalist center "underdevelops" the periphery...The overarching barrier is that for people with disabilities to advance socially there must be an overall development of the economy; Zimbabwe, like all of the "Third World," is an economy mired in backwardness.

There are a great variety of social formations in the Third World and they are not static. This is immediately apparent in Zimbabwe where you find modern urban life in Harare, Bulawayo and to a lesser extent in Mutare, where 20% of the population lives; huge plantations of thousands of acres that emphasize export crops (tobacco, coffee) owned primarily by a white gentry, millions of poor subsistence farmers being crushed by the worst drought in Zimbabwe history. All this is within a nation-state whose a governing party

has been nationalist and socialist now in the middle of an economic restructuring plan to satisfy the World Bank and the IMF!

People with disabilities are not alone. The ironies, contradictions and degradation of Third World underdevelopment sweeps across every social grouping. By way of example are the ironies and contradictions that exist between women in the Third World and the issue of reproduction. In their book, *Taking Population Seriously*, Francis Moore-Lappe and Rachel Shurman consider the condition that the Third World women's security depends on their ability to produce many children and that their power and status are concomitantly derived from their children, especially sons. So it goes.

When I went to Zimbabwe, I hoped to better understand attitudes in the African-American community in Chicago by examining those in Africa. This was not the case. Chicago's African-Americans live in a community imbued by urbanity and modernity that may seem similar to those Zimbabweans living in Harare or Bulawayo but the weight of feudalism and imperialism make the attitudinal parallels difficult to track.

It is not the intent of this writing to analyze either development or theories that attempt to analyze it, but my understanding of the development dilemmas and challenges confronting Zimbabwe's disability rights movement is influenced by theories of development that have been called "Dependency Theory" or "World System Theory". The basic point is that nation states and regions are located either in the "center" (U.S., Europe, Japan) or the "periphery" (everywhere else) and that the capitalist center "underdevelops" the periphery. The relationships and modalities that operate in this "world-system" are fluid over time but always are in some way linked to the whole and primarily influenced, by (dependent on) the center.

Philip Ehrensaft puts it this way: Underdevelopment is not a condition of being several centuries behind the kinds of transformations experienced in the capitalist center but a condition of satellitization forced upon the periphery since 1500 A.D. by this very center. Integration of a peripheral power structure, which benefits from satellitization, with corporate capital from the center results in structures which permit at most a limited degree of industrialization through import substitution. Fundamental economic transformation is thus precluded with a peripheral capitalist mode of production.

(Ehrensaft, p.139)

In *Africa and the Modern World* Immanuel Wallerstein suggested that "One can date Africa's incorporation into the capitalist world economy at about 1750, (the time of the upturn of the European world economy from its century-long relative contraction) ... Africa subsequently went through three stages of development — informal empire, colonial rule, and decolonization that mark three points on a curve of ever-deepening involvement in the world economy." (Wallerstein, p. 79)

All of everyday life in Zimbabwe is informed by the southern African reality as a part of a world-system dominated by colonialism, apartheid and imperialism. A dominance that is at the same time contested by nationalist, popular, anti-systemic, and anti-imperialist movements.

The disability rights movement confronts a second major barrier that is directly linked to the first, a formidable array of backward attitudes and myths towards disability that is heavily influenced by the precapitalist socio-economic formation that is dominant in most of the country.

That is, of course, backward attitudes towards disability are prevalent everywhere. When I went to Zimbabwe, I hoped to better understand attitudes in the African-American community in Chicago by examining those in Africa. This was not the case. Chicago's African-Americans live in a community imbued by urbanity and modernity that may seem similar to those Zimbabseans living in Herare or Bulawayo but the weight of feudalism and imperalism make the attitudinal parallels difficult to track.

African attitudes toward disability are mired in superstition, buttressed by feudal influences of witchcraft and tribalism (ancestral spirits, totems). They are also promoted through much of the religious and family structures. This is especially the case in the countryside; a result of the illiteracy, isolation and poverty people in the countryside experience (most do not have newspapers, radios or television). For example, mothers in rural areas, still hide their disabled children for fear they will be identified as witches or simply isolated in the village because people are afraid they will contract the disability through contact.

This is complicated by the gap between rural and urban that reflects a profound ideological and attitudinal factor of everyday life in Zimbabwe. The backwardness of the countryside does not only reside in the country but also inhabits the mind/consciousness of many if not most city dwellers. This long-standing and entrenched barrier is problematic because of the functional, structural and cultural integration of value systems. Moreover, the urban counter-image to rural backwardness is not particularly enlightened at its best.

Obviously, these ideological and attitudinal factors have a big effect on people with disabilities themselves. As in the U.S. and elsewhere, passivity, denial, self-pity continue to isolate and hold back people with disabilities. When one talks about disability consciousness in the periphery, it is culturally and experientially determined apart from class or community. While one's relationship to production is a determinant to some degree of consciousness, because people with disabilities are so marginalized in a region that is marginalized, the disabled are almost declassed. The disability rights movement have interests linked to the other social movements for social justice but do not have the organic, historical coherence of these other movements. On the other hand, it is clear from my limited experience in Zimbabwe that SAFOD, NCDPZ and others have begun the long process of changing peoples attitudes, of informing public opinion in such a way that calls into question the worldview of many people. They are one of the movements that can be "social carriers" that change the way people think about themselves and others.

The disability rights movement has interests linked to the other social movements for social justice but do not have the organic, historical coherence of these other movements. On the other hand, it is clear from my limited experience in Zimbabwe that SAFOD, NCDPZ and others have begun the long process of changing peoples attitudes, of informing public opinion in such a way that calls into question the worldview of many people. They are one of the movements that can be "social carriers" that change the way people think about themselves and others.

A third major challenge is how this movement develops politically. What kind of analysis will its leaders bring to their struggle? I would think that any successful, "anti-systemic" social movement must call into question the existing order to provide some vision (even a partial one) of what ultimately people are fighting for.

While SAFOD and NCDPZ are politically united on the progressive, even radical principles of empowerment and self help (much like the disability rights movement in the United States), there is no proof that a broader political vision is being developed.

The success of SAFOD an NCDPZ is partially contingent on how they

politicize the disabled community and involve them in political work. This is enormously hampered by the isolation of most Zimbabweans with disabilities.There has been progress on this front though. There has been an effect SAFOD and NCDPZ are having on people with disabilities themselves. "Finally, we are seeing a growing consciousness of disabled people as a group" (Phiri) and "as disabled women" (Mamvura). These comments are supported by the growth and size of NCDPZ which has seven urban chapters and 22 rural chapters with memberships of 30 to 300 (in Harare). This is a strong testimony to the efficacy of disabled people taking control, becoming visible and making demands.

A fourth major challenge is how the disability rights movement understands and affects the political process and the confronts the question of power. This is obviously a couplet to the issue of politics and leadership.

My travel experience did provide me some very limited insight into this and I believe both SAFOD and NCDPZ have made significant gains from their organizational growth to their access to policy makers. Their philosophy of independence and militancy have yielded some results even in the short run such as the disability law in Parliament.

I know that supporters of dependency theory have been criticized for global determinism and their concentration on the primacy of the state as the agent for social change and exchange rather than production but the theory provides a general political framework and method of analysis that I feel comfortable with. In fact, in a recent book *Transforming the Revolution - Social Movements and the World System*, many of these theorists recognize the need to understand political struggle as diffuse and not just solely concerned with "state power." Wallerstein writes:

> "Once we recognize that in practice power is enormously diffuse, we can see that the conquest of power by the family of antisystemic movements involves far more than the conquest of state power, which, if not secondary in importance, may at least be secondary in temporal sequence. Whatever strategy we construct must give up this blind faith that controlling the state apparatus is the key to everything else; it may well be that everything else is the key to controlling the state apparatus" (Amin *et al*, 1990, p. 47).

During my time in Zimbabwe, I was impressed with how similar many of the stories and experiences people with disabilities have are to people with disabilities I know in the U.S. Most similarly in the U.S. are people born with disabilities who have direct experience with residential institutions, social service agencies and charities. Especially important here are the strong convictions of people who "know" these forces are in place for social control.

There has always been a lot of interest in how various institutions like prisons (Foucault), factories (Braverman) and schools (Apple, Freire) play roles in social control. Much could be learned from further research into how institutions hold back disability consciousness and organization.

Many disability rights activists in Zimbabwe, as well as those elsewhere recognize, albeit very unevenly, all this has everything to do with control, with empowerment, with knowledge and most of all, power. In writing about the conjuncture of race, class and gender in the context of power and knowledge, Nancy Hartsock noted, "The critical steps are, first using what we know about our lives as a basis for critique of the dominant culture and, second, creating alternatives. When the various "minority" experiences have been described and when the significance of these experiences as a ground for critique of the dominant institutions and ideologies of society is better recognized, we will have at least the tools to begin to construct an account of the world sensitive to the realities of race and gender as well as class. To paraphrase Marx, the point is to change the world, not simply to redescribe ourselves or reinterpret the world yet again. (Hartsock, p.172)

A lesser but still important group of challenges, include barriers like inaccessibility, organizational, funding problems, lack of qualified personal assistants, lack of interpreters; materials not accessible to the blind. Problems of everyday life that we are so familiar with in the U.S. As I said, the challenges are immense.

Fortunately this oral history of disability rights activists explodes typical stereotypes of passive, non-persons, and gives us a perspective that people do and can make their own history. That change is inevitable and it is only a question of who directs it and how quickly it occurs.

Ultimately, the paradox remains: the movement of people with disabilities is bound up by the need to see economic development occur (the accumulation and expansion of capital) and correspondingly, the emergence of modern (scientific, educated, progressive) ideas about disability while at the same time the development of a movement that insists on social justice and equality (the restriction of capital).

As Alexander Phiri told me, "We want acknowledgement as human beings with equal opportunities and rights not either as (ancestor) curses or (modern) furniture" (my parenthesis).

Underdevelopment takes on many faces and exists in very specific social formations mediated by objective socio-economic constraints and subjective, attitudinal factors. From what I observed, SAFOD and NCDPZ have forged organizations and movements that by their very nature are confronting them.

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COMMENTARY

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Over the past decade we have witnessed intensified efforts on the part of international organizations—such as the World Health Organization (WHO), Rehabilitation International (RI), the International League of Societies for Persons with Mental Handicap (ILSPMH), the World Rehabilitation Fund (WRF), and many others—to support programs on disability prevention, while helping, through a variety of programs and strategies, to ameliorate the conditions of persons with disabilities in developing countries. The success of international efforts to address the problems associated with disability in the Third World will depend—at least in part—on how well those engaged in such efforts at different levels understand and appreciate the contexts in which they offer their expertise and advice. To the extent that preventive, habilitative, and other social action programs must be responsive to the unique cultural, social, economic, and political realities that define these contexts, it is axiomatic that those offering solutions to the problem become knowledgeable about the complex array of factors that are at play in any given Third World society.

The three papers in this monograph address some of the fundamental contextual variables about which international disability experts must become

knowledgeable if they are to make meaningful contributions to the quest for effective strategies and programs to deal with the growing problem of disability in developing countries. Although the papers vary drastically in writing style and draw examples and experiences from different parts of Africa (Mallory's paper even includes a case study of Thailand), they deal with a continuum of interconnected themes. In this regard, the papers complement one another quite well.

Belief systems inform socio-cultural practices and thus also provide a context for understanding both covert and overt attitudes toward disability—although positive or negative attitudes per se cannot necessarily be inferred directly from specific beliefs. Indigenous beliefs about disability in transitional societies are often misunderstood. Similarly, the nature of the relationships that exist among systems of belief, social support and care, and attitudes toward individuals with disability remains elusive even to indigenous scholars. Robert Nicholls attempts to clarify some of these complex issues in his focused examination of the nature of indigenous belief systems and attitudes in four African cultures.

The three papers in this monograph address some of the fundamental contextual variables about which international disability experts must become knowledgeable if they are to make meaningful contributions to the quest for effective strategies and programs to deal with the growing problem of disability in developing countries.

Nicholls makes an important contribution by outlining a valid epistemological framework for understanding conceptions of disability in transitional cultures. From a sociocultural perspective, human civilizations all over the world have manifested reliance on two fundamental modes of knowledge in their effort to comprehend the universe: the sacred (also the supernatural or spiritual) and the secular (also the profane, physical, or scientific). The secular mode is empirical, and is employed to explain day-to-day matter-of-fact experiences and events with objectively verifiable cause-effect relationships. Within all civilizations, knowledge in the secular or scientific mode tends to be limited in the earlier phases of social and cultural development (Assimeng, 1987; Marfo, in press). The sacred mode, on the other hand, deals with knowledge that cannot be readily verified through objective means. Because the ability to develop objective means for verification varies from one society to another—largely as a function of the stage of technological advancement—the range of what is objectively knowable differs from culture to culture as well (Assimeng, 1987).

According to this framework, wherever scientific knowledge about the conditions of variation and deviation in human phenomena is limited, we are likely to find more so-called supernatural attributions of causation. Indeed, even in societies where scientific knowledge about the universe is appreciably high, occurrences that defy immediate objective explanation tend to engender supernatural explanations. Thus, beliefs about how witchcraft, ancestral influences, or reincarnation of deities are causally related to various forms of disability in transitional cultures reflect the fact that scientific and technological knowledge is much less developed in these societies. Generally speaking, as the objective, scientific knowledge base increases, reliance on supernatural explanations of causation diminishes—except in matters pertaining to religious faith. This proposition is empirically testable, and I think the Nkinyangi and Mbindyo study cited by Mallory supports it. This study found that only 2% of the sample of adults with disabilities attributed the cause of their condition to some supernatural cause. Remarkably, Mallory points out that as much as 60 to 70 percent of the sample had no formal education. Certainly, if beliefs about disability were to be measured in any transitional society over a long period of time, say 20 to 30 years, a trend toward more reference to objective, physical factors will be found.

Equally important is Nicholls' point that the epistemological outlook of traditional Africans reflects a dualistic regard for both natural and supernatural causation. He notes how the Igede make a clear distinction between impairments that occur as a result of accidents and ageing (objective causation) and impairments that result from birth defects about which these people had little or no objective (scientific) knowledge. Contrary to the popular depiction of traditional Africans as being "incurably religious" (e.g., Mbiti, 1969), it is not the case that supernatural causation is invoked to explain all forms of disability. An important inference that can be drawn from Nicholls' contribution—and from my observations here—is that it is no longer valid to view superstition and supernatural causation as the sole determinant of the beliefs and attitudes that Africans or members of any other transitional society manifest toward disability and individuals with disabilities.

While crediting Nicholls for the rich account of the complex nature of indigenous belief systems, I do not think his attempt to counter "the unfortunate stereotypes about African societies that are so prevalent in the West" proved successful. Nicholls makes some value judgments that are perhaps not altogether logically consistent with his own epistemological framework. He classifies reports that tie African beliefs and conceptions about the etiology of disability to witchcraft or ancestral and other forms of divine retribution as "negative reports. He implies that these kinds of reports reflect an Eurocentric bias in the study of traditional belief systems and practices. I agree with Nicholls that there is a great deal of Eurocentric bias—perhaps Eurocecentric blindness is more appropriate—especially in the interpretation

of indigenous beliefs and practices by Western scholars. However, in this case I think the dichotomy that is created between "positive" and "negative" ways of viewing African beliefs and practices is a false one. For instance, he cites the tendency among the Ga of Ghana to treat "the feeble minded" with awe, kindness, and gentleness as a "positive example. Nevertheless, this manner of treating the "feeble minded" ostensibly derives from the belief that a person who is retarded may be the reincarnate of a deity. In effect, Nicholls is suggesting that attributions pertaining to witchcraft are negative while those pertaining to the reincarnation of deities are positive.

In my view, neither of the two kinds of beliefs—belief in witchraft or divine retribution and belief in disability as a manifestation of a deity's reincarnation—can be said to be inherently negative or positive. Indeed, both types of belief belong to the same epistemological category—the domain of the sacred or supernatural. Thus, if the charge of ethnocentrism is relevant at all, emphasizing African belief in witchcraft is no more Eurocentric than emphasizing belief in disability as a manifestation of a deity's reincarnation.

Obviously indigenous beliefs alone do not provide the total context for understanding the nature of attitudes and how they change over time. A broad range of historical, social, economic, and political forces play a significant role both in the shaping of attitudes and in the inducement of attitudinal change. Bruce Mallory provides this broader perspective in his socio-historical analysis of the forces within transitional societies that undergird the dynamics of attitude change. I think that Mallory's framework does justice to the complexity of the issue of beliefs and attitudes toward disability in developing countries. Rather than viewing belief systems and attitudes as reflecting static dimensions of indigenous cultures, the author makes a compelling case for the manner in which a broad range of variables operating both from within and outside a culture dynamically shape the conceptions and attitudes that Third World societies hold about disability.

The only critical comment I have about Mallory's paper is that the various factors presented under the six emergent themes extracted from documents submitted by the 40 respondents from developing countries could have been presented with more elaborate explanations. The author's declared intention was to have these themes serve as a guide for further research; however, there is not enough substantive discussion of how, why, and at what level of analysis some of these issues might be approached. I do not want to lose sight of the exploratory and preliminary nature of the analysis; nevertheless, the "Examples from Zaire, Kenya, and Thailand" could have been more effectively linked with the six themes by presenting and discussing at the end of each case study the manner in which specific questions raised under the six themes were exemplified and could be explored in future research.

Finally, James Charlton makes effective use of the personal stories of individuals with disabilities to not only describe the status of attitudes toward disability in the Southern Africa region but also chronicle the strides being made by organizations of individuals with disabilities toward self-empowerment and public education. Charlton's approach teaches us that we can learn a lot about the disability rights movement by talking directly to individuals with disabilities who have been at the forefront of the movement. This is not in any way intended to suggest that individuals with disabilities are the only credible sources of information about the movement. It also teaches us that qualitative inquiry of the nature shown in the life stories reported in this paper is a very rich source of data about how individuals with disabilities feel about society's attitudes toward them.

That the disability rights movement has grown so strong and been so successful in attracting the attention of government in Zimbabwe attests to the potential benefits of self-empowerment on the part of individuals with disabilities. For these benefits to be realized fully, however, it is critical that the emerging organizations of individuals with disabilities be able to forge strong working partnerships with local NGOs, international organizations, and national governments.

What would have been additionally helpful in Charlton's paper are some comments about the historical context that sets Zimbabwe apart from other African countries. To what extent are the successes made by the disability rights movement a function of the country's unique political history? How is the movement impacting the quality of services for individuals with disability? What lessons can be drawn from the dependency relationship that seems to have developed between the emerging self-empowered disability rights groups and traditional advocacy groups? Addressing questions of this nature would have added significantly to the breadth of this analysis.

I like to conclude my commentary by highlighting a number of intriguing dilemmas that both Charlton and Mallory bring to life in their analyses. These dilemmas have profound implications for the future of policy and service delivery. First, the reality of economic underdevelopment tends to foster national development strategies in which programs for habilitating or rehabilitating individuals with disability are often not a national priority. Fortunately, in many developing nations local nongovernmental organizations (NGOs) and international agencies have done an excellent job not only raising awareness about the needs of individuals with disabilities but also

developing and implementing services. The dilemma is that NGOs, by virtue of their limited resources, are only able to serve a small percentage of individuals with disabilities; yet their often high-profile presence gives the false sense of complacency that a lot is being done about the needs of individuals with disabilities. Thus, while NGOs play a crucial role in developing countries, their presence sometimes serves to enable governments to shirk their national responsibility towards individuals with disabilities.

Part of the solution to this dilemma can be found in Charlton's paper. It is crucial that organizations run by and for individuals with disabilities assume a stronger role in shaping public policy. That the disability rights movement has grown so strong and been so successful in attracting the attention of government in Zimbabwe attests to the potential benefits of self-empowerment on the part of individuals with disabilities. For these benefits to be realized fully, however, it is critical that the emerging organizations of individuals with disabilities be able to forge strong working partnerships with local NGOs, international organizations, and national governments. Unfortunately, however, as Charlton's paper shows so vividly, these partnerships are often not based on a clear-cut commonality of purpose. The fact that organizations run by individuals with disabilities often lack the financial resources to be self-supporting places them in a dependency relationship with NGOs. Consequently, the kinds of programs for which support is provided are not always ones that "correspond with the realities" of individuals with disabilities. Thus with all the progress that has been made in the last decade—in terms of the encouragement given to disability groups to organize themselves and in terms of the partnerships that are emerging among local NGOs, international funding agencies, and national governments—true independence in determining their own "destiny" very much remains elusive to individuals with disabilities in the Third World. The continued importance of the issue of self-determination is underscored succinctly by one of Charlton's interviewees:

> We have always stressed our independent role, that disabled people must control the issues that directly affect us. Our principles are self representation, emancipation, and self determination and independence.

Another dilemma arises out of the export model of providing habilitation and rehabilitation services. In some regards, the advent of Western-style services has contributed to a weakening of the commitment that families and communities have traditionally had toward members with disabilities. New service delivery models must find ways to restore and respect the important role played by family and community supports. The World Health Organization's Community-Based Rehabilitation approach is a significant step in the

right direction, although the extent to which even this approach has been successful in incorporating indigenous technology, practices, and supports remains to be assessed. As Mike Miles (1990) points out, even under CBR there continues to be a tendency toward discounting the reality that "the great bulk of care, treatment, therapy, and rehabilitation of disabled persons has always been given, is still given, and—for the foreseeable future—will continue to be given by relatives, neighbors, traditional practitioners, and disabled people themselves" (p. 249). The apparent pretence that there is no habilitation or rehabilitation where no Western forms of intervention exist is a disservice of grave proportions to the developing world.

Disability specialists and social science researchers with interest in disability issues must respond to the challenge of finding meaningful ways of interfacing indigenous care and habilitation practices with dimensions of Western approaches that make sense in the context of Third World environments.

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Rejoinder to Kofi Marfo's Commentary

Robert W. Nicholls

Kofi Marfo's commentary is insightful and helpful considering the varying approaches of the three authors and more importantly the different African nations that are featured. The extent to which each African nation has been impacted upon by colonialism, Christianity, Islam, and agents of modernity such as missions, secular education, and mass media varies considerably. Some nations such as Zimbabwe, and to a lessor extent, Kenya, have a significant European "settler" population, while others such as Nigeria do not. All of these factors naturally have affected African perceptions of disability.

Marfo articulates a dichotomy between secular and sacred as epistemological poles. The assumed superiority of the former is inherent in his statement depicting the lack of secular or scientific knowledge, in "the earlier phases of social and cultural development" (emphasis added). Although it can be argued with some justification that knowledge based on scientific facts is more reliable than that based on metaphysics, it is not so easily demonstrated that attitudes or behavior based on secular knowledge are necessarily superior to attitudes or behavior based on spiritual beliefs. By confusing beliefs with behavior, Marfo seems to mistake the intent of my essay. Rather than contrasting sacred beliefs with secular knowledge, my essay contrasts "blind superstition" with "pragmatic spirituality," and suggests that outsiders tend to view indigenous African beliefs in terms of the former rather than the latter. My estimation of what is negative and what is positive is not directed at beliefs per se, but at their affects in terms of behavior. For example, attributions pertaining to witchcraft or ancestral retribution can be considered negative if, as a result, an individual with a disability is blamed, despised, or ostracized. By the same token, attributions pertaining to "reincarnation of deities" (to pursue the example of the *Ga*) can be considered positive if, as a result, an individual with a disability is treated with "kindness and gentleness."

Although resisting the evolutionary overtones of Marfo's concept of "earlier phases of social and cultural development," with its pejorative connotations, to an extent my essay does harken back to a "pristine state" before traditional culture was contaminated, so to speak, by colonial contact. In an ideal (and possibly idealized) situation, traditional beliefs and culture represent a complete and balanced system, in which notions of good and evil, right and wrong, fair and unfair, deity and witchcraft, are counterpoised

against each other. As Christianity (and to a lesser extent Islam) arrived it broke in this closed system and tended to subvert the positive notions-goodness, righteousness, justice, etc., to its own ends and saddled traditional culture with the residue. That is why, today, in the minds of many, Africans as well as Westerners, much negativity is associated with traditional beliefs—witchcraft, superstition, juju, and so forth.

Finally, a consideration of *Ndembu* healing rituals, *Igede* notions of *Apuruja*, and *Yoruba* ideas concerning *Obatala* and *Abiku*, demonstrates that in some cases (not all) a spiritual perception of disability and its causation can promote accepting and enabling attitudes. As shown by the theories of Jung, Roszak, Read, and Beier, to simply dismiss such behavior as "pre-scientific" is to miss the point. Some might find Marfo's term "Eurocentric blindness" an appropriate description of this situation.

APPENDICES

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APPENDIX A
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APPENDIX B
Sample Responses to Seven Questions

❖

Question 1

In what way are people with disabilities viewed in your society, and how is that changing or not changing?

❖ Some religious groups accept the disabled as normal human beings, some feel that they are products of cultural violation, cursed, reject of the gods; while others use them as sources of income of the family.

The view is changing in that some citizens ignore the disabled while some contribute to their welfare. *(O. S. Afolabi, Nigeria)*

❖ The major causes of disabling impairments in Uganda are malnutrition, communicable diseases, low quality of prenatal care and accidents (including violence). These are responsible for about seventy percent of all cases of disability in Uganda. The common disabilities are physical disability, mental disability, visual disability, hearing and speech disability. The problems related to disability vary greatly among areas within each district in Uganda. The nature of the disability problems are influenced by the level of economic and social development and by other factors such as climate, population distribution, availability of food, water, and social cultural systems. The disabled often have to depend on others for performing daily-life functions. Individuals and families may be aware of their own problems, but they have limited knowledge about what can be done to solve or to lessen them. *(E. Madraa, Uganda)*

❖ People with disabilities continue to be viewed as useless people who need care until they die. The care, however, is not transformed into action. The responsibility continues to be of the government. In areas like big cities, the views of society are changing as the society has been exposed to people with disabilities. *(P. Dube, Zimbabwe, Africa)*

❖ Until about half a century ago, the common man did not realise the potential of people with disabilities and that, with education and training, they could very substantially contribute to their own and family upkeep and assist in promoting the general development of the country. After independence in 1947, this approach has changed and the realisation is fast growing that people

with disabilities can contribute and be independent members of society. In the last decade in India the change is quite noticeable. (Capt. H.J.M. Desai, India)

❖ On the whole, people with disabilities are reasonably well accepted in New Zealand. However, there are particular groups of people such as those with major hearing difficulties and psychiatrically disabled which are fairly misunderstood. I believe a lot of difficulties in these areas are caused because these groups are not as well coordinated as those with intellectual and physical difficulties. *(Paul J. Curry, New Zealand)*

❖ In New Zealand, people with disabilities are viewed somewhat negatively. There are few times when someone with a disability, as compared with someone without, would be viewed positively. Stigma, discrimination, prejudice and ignorance are not universal here, but are known and experienced occasionally by most people with disabilities.

I note a small but intriguing difference here in New Zealand, Pakehas, or white descendants of Europeans are "individualised", just as are people in the USA, to a greater extent than are Maori people, who recognise and maintain membership in family, tribal, and other related groupings. The Maori individual is not necessarily the focal point to the same extent and degree culturally, and though an individual may have a disability, the supportive social structure offers a different climate, which prevents or ameliorates "disability" in a way different from that of Western cultures.
(Robert J. Gregory, New Zealand)

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Question 2

In what ways have the availability of programs and services been improved (or not)?

❖ Improved programs and services increase because of Government funding and increased awareness created by the N.G.O.s.
(O. S. Afolabi, Nigeria)

❖ Although there have been nationwide programs geared towards the improvement of health services through primary health care, no progress has been made with regard to disability. Mortality among disabled children is much greater than that among unimpaired children (unfortunately no statistical figure). Malnutrition and gastroenteritis and bronchopulmonary infections are the main causes of death among disabled children (e.g. children with blindness, mental retardation, and those with mobility difficulties). The disabled children have less opportunity to attend school than normal children.

The presence of one child with visible and stigmatizing disabilities in a family has negative consequences for the marriage of not only the disabled child but also for that of the other siblings. In many societies the disabled are often segregated because of deep-rooted fears and beliefs, originating from age-old cultural and religious convictions such as those people with disabilities are possessed or under divine punishment. Disabled persons are very often excluded form any position of leadership in the communities, they are seldom elected or appointed to any political office and are excluded form planning and decision-making in the societies. This almost complete lack of representation in community affairs results in neglect of their needs, leads to prejudice, misbelief, and fear, which in turn unfavorably influences the attitudes and actions of the local community and government. *(E. Madraa, Uganda)*

❖ The Ministry of Health through the Rehabilitation Department has embarked on a community based rehabilitation programme which aims at reaching as many people with disabilities as possible. *(P. Dube, Zimbabwe)*

❖ The government of India Report on Blindness, 1944 states that there were 32 Institutions for the Blind in the country. Now the number of institutions is well over 250. In addition, there are some 50 Associations working for prevention of blindness and the general welfare of the blind and the visually handicapped.

Programmes and services for people with disabilities in India, in recent decades, are very substantially improved. This is as a result of studying the programmes, projects and services in progressive countries and adapting them to the needs of our country with such changes as may be necessary. In a predominantly rural country like India, eighty percent of the disabled live in the rural areas, where the facilities are meager or non-existent. However, the concept is slowly spreading into some of the 5,050,000 villages in India. *(Capt. H.J.M. Desai, India)*

❖ As to change, IYDP, the Disabled Persons Assembly, and the gradual movement from a "social welfare" state to a free market economy have together opened up opportunities for New Zealanders who happen to have disabilities. Unfortunately, though, while there is greater recognition of rights, the Human Rights Act does not extend to people with disabilities. Though there is greater interest (and need) among people with disabilities in employment, the labour market has come under sever stress. The Labour government passed equal employment legislation which has been repealed by the recently elected National Party.

One intriguing change I have witnessed here came from "The Helmet

Lady!" Rebecca Van Oaten has a son who was hit by a car, and has severe head injury. She has successfully initiated and led a campaign so that helmets are worn by bicycle riders and motorcycle riders almost universally. She has spoked about prevention of head injury to virtually every school in the country. She has worked tirelessly so that fewer young people encounter head injuries. Her story is quite remarkable. *(Robert J. Gregory, New Zealand)*

❖ The major changes happening on the New Zealand scene at this stage is the Government's investigation into the possibility of providing benefits and services via an individual based funding method. This method (if approved) will mean that the person with a disability will receive an entitlement for particular services which they will be able to contract for from a service agency.

This should also give people the ability to, if they are not satisfied with the services, provided they will be able to remove their entitlement and therefore make sure that the service agency receive knowledge that they have not met the consumer's needs.

In addition, a pilot brokerage programme was complete in Palmerstown North in 1990. This programme was introduced by Mr. Brian McKenny who is currently a broker with the Vancouver Living Society in Canada. His knowledge and expertise assisted a Palmerstown North group to identify that the brokerage system worked very well. Since that time a society known as the Options in Community Living Society has been formed and the brokerage system now offers a full service to people in Palmerstown North. We believe that this concept is the way of the future, where an individual can get a personal plan prepared in consultation, and on the his/her behalf, when either the individual or an advocate can negotiate with service providers for the identifying programmes and services to meet their needs.
(Paul J. Curry, New Zealand)

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Question 3

What has been happening there regarding personnel training and professional standards?

❖ Problems still exist with regard to the personnel training and the meeting of professional standards. Bob Gregory runs a very good course in Rehabilitation Studies at Massey University and there are a number of other approaches being put together to establish other training programmes throughout the country. An interesting point is that increasing numbers of people with disabilities are now participating in these training programmes.

It is hoped that they will take a leadership role in the future as they move into organisations etc. *(Paul J. Curry, New Zealand)*

❖ Professional standards and practice enhance quality of service delivery, increased level of awareness serve as advocacy.
(O. S. Afolabi, Nigeria)

❖ Professional standards and practices continue to be a hindrance in the empowerment of people with disabilities. Professionals always come forward with package and the recipient is never given a chance to accept or object the package. This is because they believe they know what is best for people with disabilities. *(P. Dube, Zimbabwe, Africa)*

❖ In recent decades, employment of professionals in the rehabilitation of disabled people is very much encouraged. Professional standards and practices have substantially improved. At the same time, volunteers continue to take a keen interest. Some volunteers are doing as much as professionals.
(Capt. H.J.M. Desai, India)

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Question 4

What role do the family, school, church, and other community organizations play in enabling people with disabilities to participate in society?

❖ These structures are still a barrier as they believe in most cases in care. They believe people with disabilities should be taken care of in specialised places like institutions. *(P. Dube, Zimbabwe, Africa)*

❖ When the work for the blind started in India over a century ago, the Church played the major role. Now the family, school and the community in general all assist people with disabilities very substantially. In the past, people with disabilities themselves were advocating to receive vocational training and thereafter get employment. *(Capt. H.J.M. Desai, India)*

❖ The family, school, church etc in New Zealand are very important as the human network for people with disabilities. Quite often, they are the first people to make contact with information services etc.
(Paul J. Curry, New Zealand)

❖ In New Zealand the family quite naturally takes up a major role in enabling people with disabilities to participate in society. One of my students just completed an interesting Master Thesis on the family and head injured

members. A couple of colleagues and I completed work on a research report on people with Multiple Sclerosis and their carers, which also demonstrates that the family support is a major factor. Interestingly, there is detectable difference with the USA in that New Zealand has and uses many committees, clubs and social organizations. Most New Zealand people belong to several committees, clubs, and similar groupings which play a key role—far more important here than comparable groups in the USA. Some of these committees can and do help integrate individuals into the community, others probably could do more if pushed or invited. I would love to see further study of the New Zealand committee and club structure and remarkably it functions to support individuals who happen to be different.

Among the people at the economic bottom, and including many Maori, the phenomenon of the "gang" is prevalent. Gangs of young men especially, form and maintain very tight "family" ties. Because of the incidence of motorcycles, they are often regarded as motorcycle gangs, living on the fringes of society, but nevertheless, part of the New Zealand scene. Accidents and traumatic injuries, and sometimes violence and drugs and alcohol appear to be an endemic part of their lives. Consequently disability and rehabilitation are potentially important topics to them.

Churchgoers on New Zealand have chosen to and do play a key role in helping refugees find a place in society. People from Southeast Asia in particular have been helped through these specific efforts and I believe they play a far greater role than in the USA. A couple of my students have come up with term paper projects in this arena, and the research possibilities are many. In particular, the methods and styles adopted to "rehabilitate" refugees by the church people would be a most fascinating research endeavor here in New Zealand, as would the results and satisfaction of the refugees themselves. *(Robert J. Gregory, New Zealand)*

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Question 5

How has your country responded to needs of family members and used them as resources in the rehabilitation process?

❖ There has not been an articulate policy on this like granting tax relief to families of the disabled up-keep and such respite. By natural arrangement some families rehabilitate disabled through the extended family service support. *(O. S. Afolabi, Nigeria)*

❖ Nothing much has been done in this area as rehabilitation has not been a priority to the government. *(P. Dube, Zimbabwe)*

❖ The government and some private organizations have tried to provide some rehabilitation services however limited. Most of the services are done at the central level and convenient services in the Capital and its immediate environs. Such services cater to only one or two percent of the total number of the disabled children in the country which leaves the services practically inaccessible to the rural disabled, and the basic community services doesn't include a rehabilitation component for the disabled. Many institutions specialize in treating only certain kinds of disability which also has contributed to the limit of the effectiveness of their services. Other factors include lack of coordination between the various components of rehabilitation services, the maldistribution of educational, vocational, and health services.
(E. Madraa, Uganda)

❖ There was not much progress in getting family members to study rehabilitation practices in depth. However, traditionally, the family members continue to take interest in the disabled members of the family to the extent permitted by their limited financial resources. Most disabled people belong to the poor or middle class families.

The family members now normally seek the guidance of N.G.O.s dealing with disabilities. They also get guidance form Vocational Guidance Counsellors. There has not been much progress in using family members as resources in the rehabilitation process except among the intelligentia.
(Capt. H.J.M. Desai, India)

❖ I believe there is an embryonic movement throughout New Zealand for family members and people with disabilities to actually control the services and organisations that represent them.

Just recently the Palmerstown North Branch of the New Zealand Crippled Children Society was seen as not meeting the needs or listening to the concerns of their consumers. A vote of no confidence in the Board of Directors was put and while they fought this motion the consumers won and now have a 70% representation on the Board of Directors.
(Paul J. Curry, New Zealand)

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Question 6

How have people with disabilities themselves influenced change?

❖ Recently people with disabilities have come to form Associations of the disabled whereas decades ago, there were associations for the disabled only. This development would likely encourage the society to accelerate provision of support facilities, restore their rights etc. The chairman of Nigeria

National Advisory Council for the Blind is one of the leaders of disability Rights movement. *(O. S. Afolabi, Nigeria)*

❖ People with disabilities have challenged the idea of being viewed as objects of pity and charity. Serious presentations have been made with the President of the country and other government Ministers. This has resulted in the drafting of a disability bill that is aimed at protecting people with disabilities. Mr. A.M. Phiri is the President of the National Council of Disabled Persons of Zimbabwe. *(P. Dube, Zimbabwe)*

❖ The Disabled Persons Assembly movement in New Zealand has really been a forerunner in speaking on behalf of people with disabilities, especially with regard to "disability rights".

At a recent meeting facilitated by the Minister of Social Welfare, those people present, representing disability groups lobbied very strongly to have Human Rights Commission Legislation extended to include, Matters Relating to Discrimination of The Grounds of Disability. We believe that this will happen soon.

A number of other organisations such as the "People's Forum" have sprung up and are totally run and controlled by people with disabilities. These are more service oriented and are linked to the Disabled Persons Assembly which does not provide service. *(Paul J. Curry, New Zealand)*

❖ People with disabilities have helped force change in a number of ways in New Zealand. The most apparent is Disabled Persons Assembly (DPA) - a national organisation and umbrella group. They have been powerful in promoting social change, as in *Teletex, Total Mobility, Employment Equity,* advocacy, funding of benefits, and so on. Thanks to Anne Wasserstrom, and the funding by the IEEIR, the DPA role in advocating for and with and by people with disabilities has been well documented.
(Robert J. Gregory, New Zealand)

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Question 7

Do you feel that U.S. disability rights advocates should be working with people with disabilities in your country to help them become more aware of their place in society? What suggestions might you have in this regard? (We feel that there is a growing interest on the part of U.S. disability advocacy groups to assist people with disabilities in emerging countries to recognize their own rights and value in society. However, cross-cultural "education" often does not adequately take in to consideration values, mores and attitudes of other countries.) What

do you think U.S. disability advocates should know about your country and its disability movement before visiting?

❖ (a) yes (b) assertive training (c) enlightenment or creating public awareness (d) information about what the disabled have achieved in U.S.A. *(O. S. Afolabi, Nigeria)*

❖ There is a need for people with disabilities throughout the world to work together as they all are citizens of no country. It is important that we learn form each. This could be done by either exchange visits or by sending each other information. *(P. Dube, Zimbabwe)*

❖ It will greatly help if advocates and activists for the rights of disabled people work with each other so that exchange of experiences and information may mutually benefit the disabled of countries concerned. In addition to exchange of information, there should be exchange of outstanding activists so as to bring about a new era of concerted action for securing the basic human rights of the disabled and promote values and ideals enshrined in the superb United Nations Instruments. Fellowship studies, visits, exchange of publications, attendance at Conferences and Seminars all would greatly help *(Capt. H.J.M. Desai, India)*

❖ Many of the notions behind North American "disability rights" campaigns are peculiar to North America and to a lessor extent North-Western Europe, and are not necessarily seen as admirable by people living in many other parts of the world. A corollary of this is that the slogans of the Decade of Disabled People were largely incomprehensible to most of the world. *(Mike Miles, Pakistan)*

❖ I do believe that the disability rights advocates from the United States could be of assistance in helping to empower people with disabilities in New Zealand. There are a number of organisations who believe that they advocate on behalf of people with disabilities, unfortunately this is quite often their perception of the needs of people with disabilities and not necessarily those in fact. *(Paul J. Curry, New Zealand)*

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Additional Comments

1) Efforts should be made to promote disability prevention and rehabilitations and if is necessary that the government decides on the policies regarding it, and commits itself to the various steps in its development.

2) A community-based disability prevention and rehabilitation programme must be financed and maintained by the resource of the country and national power and should not depend on external inputs. However, this does not exclude financial support from international sources during the period of the development of the programme.

3) The integration of disability prevention and rehabilitation into the existing community services, particularly primary health care services should be made.

4) Creation of a special organization, independent of other services, should be discouraged, if a programme is developed as a government programme. Various community based services can be involved in the development such as health care teams, rural development teams, agricultural extension groups, local social services groups and primary schools.

5) A programme should be provided by either the government or the private organizations in the country to train the disabled in the community.

6) There should be provision of social integration viewed as active participation of disabled and handicapped persons in the mainstream of community life. This could be achieved by provision of adequate rehabilitation for all the disabled and handicapped and to reduce to a minimum all handicapping conditions in all aspects of their environments.

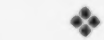
(E. Madraa, Uganda)

APPENDIX C

Lessons to be Learned from Abroad: Guiding Questions

by Bruce Mallory

Taken from the *Worldview* Column appearing in the *AAMR* Newsletter, 1989



There is a growing awareness, if not consensus, that the United States can no longer play the exclusive role of exporter of special education and habilitation practices. If recent trends in the trade of manufactured goods were to also show up in more abstract products such as knowledge of the best practices in treating people with disabilities, we could find ourselves importing more than we export. This may sound far-fetched to some, but it is a notion worth considering. Can we assume that our approaches to treatment are intrinsically more advanced and effective than approaches used in other countries, particularly developing ones? Can we assume that professional and political leaders in other countries will continue to rely on American models as templates for solving their own problems?

These questions were stimulated by a recent experience in Malaysia, where I was asked to assess a school for children with intellectual handicaps and make recommendations for its improvement. While initially flattered, I soon was overwhelmed by my own inadequacy at such a task given the very different cultural, political, and economic context of this school compared with those in the United States. My hosts were gracious and eager to the thoughts of an American "expert." But soon after, I was pleased to learn that a new attitude has developed in the Asian nations, reflected in their explicit motto, "Look to the East." This conscious desire to discover indigenous solutions, congruent with regional needs and value, is a healthy one. If it holds, and becomes widespread in other developing and non-Western nations, the consequences for American practice must be examined. To put it bluntly, we will have to suppress the tendency to lecture and cultivate the habit of listening in the emerging global community.

This assertion comes from several assumptions about the future of special education and habilitative practices in the United States. First, we know that the school-age population is becoming increasingly heterogeneous. By the beginning of the next century, about one-third of all American school

children will belong to a racial or ethnic minority. This alone will create pressures to be less ethnocentric in our practices and more open to applying culturally diverse solutions to our schools. Second, the economic pie for social programs is likely to get smaller, and the number of problems competing for slices of the shrinking pie will get larger. That, is, the resource base for special education and habilitation programs may begin to resemble that of less affluent countries. Third, medical advances will contribute to increased incidence and prevalence of people with serious disabling conditions. The ethical, economic, and social consequences may parallel conditions in other countries experiencing similar patterns. Fourth, the commitment to communitization that has characterized American practices for the past 20 years will continue to be fragile, and may show real signs of erosion. The experiences of other countries in which the commitment has fluctuated could be applicable here. Finally, there is no question that the role of the United States as a political and economic leader in today's world has eroded, and will continue to do so. This will require greater humility and adaptability, including a willingness to examine and adapt the ideas of emerging world leaders, such as those nations located along the Pacific rim.

Whether or not these assumptions hold true, it is still important to be a receiver of knowledge as well as a transmitter. Let me suggest several questions that could be asked to gain a better understanding of issues related to social policy, treatment practices, and ethical problems in other countries.

1) How do political and economic ideologies influence the design and delivery of habilitative and rehabilitative services? For example, do people with disabilities always belong to surplus populations in capitalists economies, as Bernard Farber argued? What are the role and status of people with disabilities in socialist economies? How are people who clearly deviate form social norms assimilated in societies that value social cohesion and conformity over individual achievement?

2) How do various societies define and categorize developmental differences?

3) What is the relationship between social policy and voluntary action in other countries with respect to the care and treatment of citizens with disabilities?

4) In societies with extremely limited social welfare resources, how are priorities established to determine who receives services? What is the relationship between the level of resources and institutional vs. community-based care?

5) What is the role of professional standards of practice in other

countries? What sanctions are available when professionals abuse the rights of clients? Who establishes these standards and sanctions?

6) In the absence of constitutionally-based mandates and safeguards, how are the rights of people with disabilities that were articulated in the United Nations Charter on Human Rights protected?

7) How are ethical problems such as abortion of defective fetuses, treatment of seriously ill newborns, and use of coercive intervention models handled in other countries?

8) What role do mediating social structures (Family, school, church, voluntary organizations) play in enabling people with disabilities to participate in society?

9) How have other countries responded to the needs of family members and incorporated families as resources in the treatment process?

10) What is the role of technology in other countries in areas such as treatment, communication among professionals, outreach to remote communities, and program management?

The answers to these questions could provide insights on practice in the United States and countries facing similar circumstances. Currently, there are few channels for gaining answers. Some ways to increase our cross-cultural awareness include the creation of international divisions in professional organizations, including the AAMR, more cross-cultural literature in our professional journals and texts used for professional preparation, sponsorship of foreign experts to lecture in the United States, international exchanges of experts in policy and program roles as well as the traditional university roles, and international coalitions of parent/family organizations.

There is no single entity that can stimulate this more global perspective. It will be up to all of us to be more curious about what happens beyond our borders, and to be curious not merely in an anthropological way. Our interest in other cultures and their practices must come from a recognition that the distinctions between American and foreign contexts are likely to lessen in the future. Perhaps the time has come to "burn down the mission," as Elton John would say.

APPENDIX D
IEEIR Fellows
Whose studies are relevant to the topic of this monograph

Sharan E. Brown, Ed.D. Research Assistant, University of Washington. **Lane Gerber, Ph.D.** Professor, Department of Psychology, Seattle University. Topic: *Development of an Integrated Healing Model to Address the Mental Health Crisis Among Khmers* (Cambodia): (December 1991 - January 1992).

Pauline E. Ginsberg, Ph.D. Associate Professor of Psychology, Utica College of Syracuse University, NY. Topic: *Psychiatric Rehabilitation in Kenya: Applications to the Rural U.S.* (July - August 1992).

Stewart D. Govig, Ph.D. Professor of Religion, Pacific Lutheran University, Tacoma, WA. Topic: *Health Professionals, Families, and Long-term Mental Illness: A Chinese Traditional Medicine Collaboration Model* (Hong Kong): (August - September 1992).

Jocelyn Armstrong, Ph.D. Associate Professor, University of Illinois at Urbana-Champaign. Topic: *International Exchange in Development of Rehabilitation-Related Education: The United States and Malaysia* (May-August 1992).

Charlene Butler, Ed.D American Association for Cerebral Palsy and Developmental Medicine. Topic: *Innovative Ideas in Educational, Medical and Social Care of Disabled Children in Greece, Turkey, Africa, India and Southeast Asia* (August 1991-August 1992)

Jean Compton Topic: *Community Based Rehabilitation: How to Incorporate Community Volunteer Organizations and Family Members to Implement Program* (India): (September-October 1992).

Dennis Harper, Ph.D. Professor of Pediatrics, University of Iowa. Topic: *Social Preferences of Maori Children Toward Visible Physical Impairments* (New Zealand): (March-April 1993).

Eva Friedlander, Ph.D.; Sally Deitz, Ph.D. Topic: *Family Focused Care in a Kin-Based Society in India.*

Sajani M. Thadani, CSW. Topic: *Community Based Worker: A Model of Psychosocial Rehabilitation in India.*

Richard Culp Robinson Topic: *Leadership and Management of Rehabilitation Services for Economic Development with Persons with Disabilities—a participatory and qualitative case study of beliefs, social policy , and resource allocation in a rural and an urban African community. (Zimbabwe)*

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